
**SCHOOL OF PSYCHOLOGY**

**DOCTORATE IN CLINICAL PSYCHOLOGY**

**MAJOR RESEARCH PROJECT**

# Couples facing adversity through stroke and malignant brain tumour: a qualitative investigation.

Submitted by Siobhan Betts to the University of Exeter as a thesis for the degree of Doctor of Clinical Psychology in May 2019.

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**Signature:**

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**DOCTORATE IN CLINICAL PSYCHOLOGY**

**LITERATURE REVIEW**

# The positive impact of stroke on the couple relationship from the perspectives of patients and spousal carers: a thematic synthesis of the qualitative literature.

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**Abstract**

*Objectives:* Historically most qualitative research on the couple experience of stroke has focused on the negative impact, including reviews that outline challenges for couple's communication, roles and intimacy. The current review aims to examine the perceived positive impact of stroke on couple relationships from the perspective of stroke survivors and spouses.

*Methods:* Relevant qualitative literature was identified through systematic searching of the databases Medline, PsycInfo and EMBASE. Thirty-two articles met the inclusion/exclusion criteria. The articles were appraised using the Critical Appraisal Skills Programme tool and a thematic synthesis was conducted on the findings from these articles.

*Results:* Ten descriptive and three analytical themes were identified. The analytical themes showed a strengthening of the couple bond, an enhanced way of couple's relating and empowerment of the spousal caregiver in the stroke survivor's recovery.

*Conclusions*: The review identifies that couples can engage with dyadic coping and enhance their pre-stroke relationship through the experience of stroke. Rehabilitation staff, inclusive of clinical psychologists, can play an important role in engaging and empowering couples to recognise and utilise their strengths and resilience. Future research could examine how rehabilitation can utilise these findings in practice and the efficacy of couple's therapy in this population.

*Keywords:* Stroke, Couple, Relationship, Positive Impact, Dyadic Coping

*Implications for rehabilitation*:

- Rehabilitation staff could play a pivotal role in recognising dyadic coping in couple's post-stroke. Staff could facilitate conversations between couples in order to empower couples to recognise their strengths and resilience as a dyad.
- Those couples whom are struggling to engage in dyadic coping may benefit from psychological interventions, including systemic couple's therapy in order to enhance dyadic coping.

## Introduction

Stroke occurs when the blood supply to the brain is disrupted or altered (National Health Service, 2019). There are two mechanisms of stroke: ischaemia and haemorrhage (Chung, 2017). 85% of strokes are ischaemic, where there is a blockage and blood cannot get to parts of the brain, and 15% of strokes are haemorrhagic, where there is bleeding in or around the brain (Stroke Association, 2018). A transient ischemic attack (TIA) is a 'mini' stroke where the majority of symptoms resolve within twenty-four hours; however, these neurological events are a risk factor for stroke (Hu, Heyn, Schwartz, & Roberts, 2017).

From data in 2004 by the World Health Organization, it was estimated that there are approximately 30 million stroke survivors globally (Mathers, 2008). Stroke can affect one's physical abilities (Crichton, Bray, McKevitt, Rudd, & Wolfe, 2016), cognitive abilities (van Rijsbergen, Mark, de Kort, & Sitskoorn, 2014), personality (Stone et al., 2004) and ability to comprehend and express emotions (Ashley, Lee, & Heaton, 2019; Binder, 1984). Denier and colleagues (2016) provide evidence to suggest the prevalence of stroke survivors experiencing aphasia, a difficulty with communication, is between 15-40%. All of these factors might impact on social and everyday functioning for the stroke survivor. Challenges for stroke survivors can include returning to work (Ashley, Lee, & Heaton, 2019) and managing childcare for younger stroke survivors (Teasell, McRae, & Finestone, 2000). Enderby and colleagues (2017) suggest a holistic approach to stroke rehabilitation so interventions encompass cognitive, social, physical and emotional elements. The researchers advocate for the dynamic nature of the rehabilitation needs of stroke survivors and how this should be regularly monitored and responded to.

## Impact of Stroke on Relationships

The impact of stroke can be profound for the stroke survivor, the spouse and the family. For the purpose of this review, the terminology ‘stroke survivor’ and ‘spouse’, or ‘couple dyad’ will be used. Thompson and Ryan (2008) conducted a review of the impact of stroke on the spousal relationship, examining qualitative and quantitative articles. The researchers identified the following themes: “coping, adapting, and adjusting”, “role, identity and work”, “emotional issues and poststroke fatigue” and “sexual function, and sexuality”. The themes captured positive and negative aspects of the experience of stroke; however, the literature has largely focused on the negative impact on couples and family life. For example, the review by Ostwald (2008) identified challenges for couples and families with respect to family functioning, communication, the evolution of family roles and sexual intimacy. When examining the literature on male stroke survivors and female spousal carers, researchers identified a shift in attitude where the couple’s perceived themselves as less able to function effectively (Green & King, 2007). From the perspective of spouses, stroke can alter roles in the couple dyad as well as lead to a sense of uncertainty, loss and fear about what the future might hold (Greenwood & MacKenzie, 2010). Research has also looked at intimacy and sexuality following stroke. A systematic review was conducted by McGrath, Lever, McCluskey and Power (2019) on the impact of sexuality on stroke and identified two analytical themes: “sexuality is silenced” and “sexuality is muted and sometimes changed, but not forgotten”. This identifies an alteration in intimacy post-stroke but also the sense it is a taboo subject to discuss.

Research has shown that spousal caregivers of stroke survivors can experience challenges in their role as caregiver. Godwin and colleagues (2013)

discovered that in the first year following discharge, spousal caregivers experienced higher perceived stress and lower perceived mutuality (closeness, pleasure and comfort) than stroke survivors. This supports wider research about the challenges of caregiving of a stroke survivor: caregiving as demanding in nature (Coombs, 2007) and lonely (Tunney & Ryan, 2014). The challenges spouses face in adapting to their new roles as caregivers has also been examined (see for example Quinn, Murray, & Malone, 2014; Woodford, Farrand, Watkins, & Llewellyn, 2018). It could be hypothesised that the difficulties experienced by caregivers has an impact on the relational dynamic of the couple.

Several studies have explored the resilience of couples when facing recovery from stroke. The ability of married couples to show flexibility and adaptability in order to re-establish the couple relationship following stroke has been documented by Anderson, Keating and Wilson (2017a). A review by MacKenzie and Greenwood (2012), examining both qualitative and quantitative literature, observed the positive experiences of spousal caregiving in stroke. The findings highlighted that spouses noted a strengthening of the couple relationship as a result of the experiences of stroke; furthermore, the caregiving experience was described as meaningful and confidence-building for spouses. Godwin and colleagues (2013) identified that those spousal carers who reported higher mutuality perceived their stress to be lower. The researchers advocate for the importance of interventions engaging couples in the positive aspects of their relationship in order to reduce stress. This may highlight the need to consider implementation of the findings in rehabilitation context.

## Dyadic Coping

Dyadic stress can be experienced by both partners directly or indirectly. Dyadic coping is a systemic idea that conceptualises how couples face adversity through utilising different strategies (Bodenmann, Falconier, Randall, 2017).

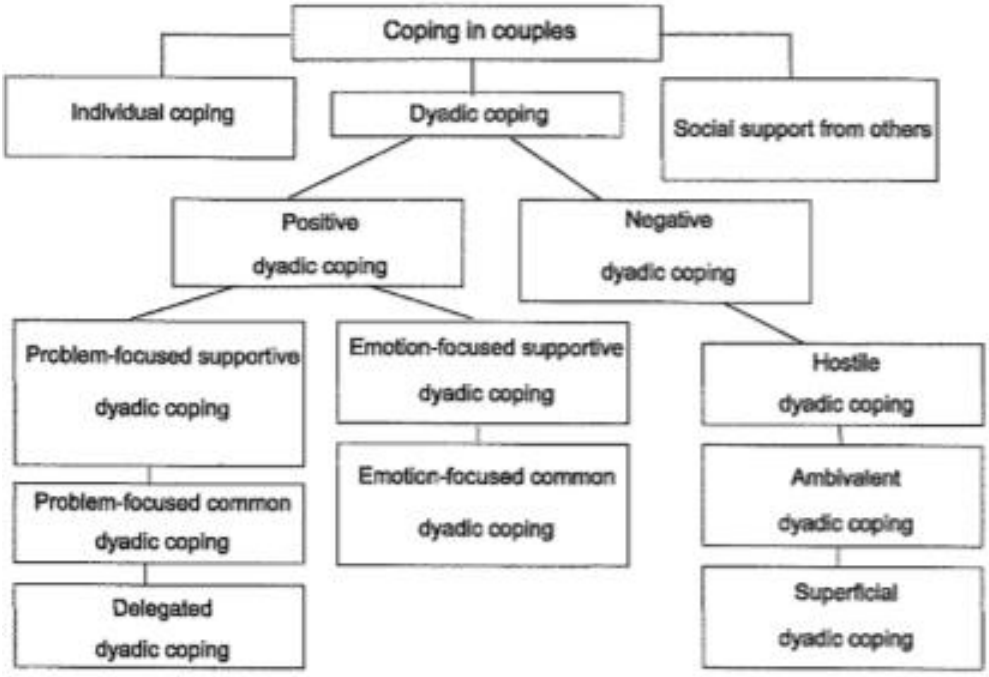


Figure 1: *Model of dyadic coping taken from Bodenmann (2005)*

Figure 1 shows the many forms of dyadic coping (Bodenmann, 2005). Positive dyadic coping can be categorised as problem or emotion focused in nature, or supportive or common. Problem-focused may relate to the couple problem solving or information gathering, whilst emotion-focused may relate to the couple offering empathy to one another, sharing feelings or co-regulation of emotional states in the dyad. Common Dyadic Coping is where the couple jointly support each other, and Supportive Dyadic Coping is where one member of the dyad supports the other. It is facilitative in reducing stress in the individual and partners, as well as improving the quality of the couple relationship

(Bodenmann, 2005). A by-product of dyadic coping is partners experiencing togetherness in the couple relationship (Bodenmann, 2005).

As identified in Figure 1, dyadic coping can also take a negative form through supporting one another in a manner that is experienced as superficial, ambivalent or hostile within the couple dyad.

This concept has been used to explain coping within couples in many different contexts, including chronic illness (Berg & Upchurch, 2007), metastatic breast cancer (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010), haematological cancer (Pankrath et al., 2018) and head and neck cancer (Badr, Herbert, Bonnen, Asper, & Wagner, 2018). This theory will be used to contextualise the findings within this review.

**Systematic Review Rationale**

Lou, Carstensen, Jørgensen and Nielsen (2017) conducted a review of the qualitative systematic literature reviews that have been published on the experiences of carers and survivors of stroke. Overarching themes identified from the seven reviews were: “autonomy, uncertainty, engagement, hope and social relations” (page 309). The theme of social relations was evident across all the reviews and encompassed the broad difficulties of maintaining interpersonal relations. Lou and colleagues outlined that there has been a rich amount of qualitative systematic literature reviews conducted in this area and set out to identify topics for future reviews. Examining the benefits of caring was recommended. To date, no published literature review has explored the positive impact of stroke on a couple’s relationship dynamic. Thus, the aim of the current review is to enhance the knowledge in this field with the hope of generating recommendations for clinical practice for staff working in rehabilitation services.

The rationale for focusing on couples is that the couple dynamic is a unique relationship that differs to the support received from significant others (Bodenmann, 2005). This is reflected in the amount of literature exploring the impact on the couple dynamic of stroke; however, there is less consideration of the impact of these findings on stroke rehabilitation (Ostwald, 2008). Qualitative reviews on the experience of stroke for survivors and spouses have thus far neglected what can be learnt from couples who are coping well, or reflections on coping from couples who have struggled, in order to facilitate those couples who are in need of support.

**Aim of the review.**

The following research questions are considered in this review:

- What is the perceived positive impact of stroke on the couple relationships?
- What are the perceived strengths of couples who have experienced stroke?

# Method

## Screening Procedures

Qualitative studies which highlight the positive impact of stroke on a couple relationship were systematically identified and critically evaluated using the Critical Appraisal Skills Programme (CASP, 2018).

The guidelines set out by the Preferred Reporting Items for Systematic reviews and Meta-Analyses checklist (PRISMA; Liberati et al., 2009) were utilised, alongside the SPIDER framework (Cooke, Smith, & Booth, 2012) which focuses on the ‘Sample, Phenomenon of Interest, Design, Evaluation and Research Type’ of relevant articles. This framework was used to clarify which articles would be included in the review. The inclusion and exclusion criteria are presented in Table 1 using the SPIDER framework.

Table 1
*SPIDER framework for inclusion and exclusion criteria*

| | Inclusion | Exclusion |
|---|---|---|
| Sample | • Couples where one of the partners has had a Stroke or TIA<br>• Survivors of stroke or TIA<br>• Partners of survivors of stroke; may be married, unmarried, cohabiting or not cohabiting | • Research where participants are not currently in an intimate relationship<br>• Couples where an individual has not had a stroke or TIA<br>• Research that focuses on or includes stroke survivors who have aphasia or dysphasia, or their caregivers |
| Phenomenon of Interest | • Positive experiences or sense making, benefits or satisfactions on the relational impact of stroke on couples<br>• Positive experiences from the perspective of the survivor, the partner or the couple on the couple relationship | • Research that does not discuss any positive impacts of stroke on the couple relationship<br>• Research that only focuses on the negative impact on the couple relationship or challenges including caregiver burden or strain |
| Design | • Qualitative design, including interviews, focus groups, couple interviews | • Editorials, systematic reviews, case reports, discussion articles, thesis, dissertations<br>• Non-peer-reviewed articles |

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|---|---|---|
| Evaluation | • Qualitative analysis on the impact of stroke on the intimate relationship i.e. intimacy, couple roles, relationship quality, stability, communication, conflict management<br>• Analysis includes thematic, discourse, narrative and interpretative phenomenological analysis, grounded theory | • Quantitative analysis or mixed methods analysis |
| Research type | • Primary research<br>• Peer-reviewed research<br>• Qualitative<br>• No date limitation | • Quantitative measures<br>• Mixed methods<br>• Articles that have not been published in English or where the publisher has not provided an English translation of an article published in another language |

The rationale behind excluding papers that focus on those who are experiencing aphasia is that aphasia is a specific type of disability and the focus of this review is on the general stroke population. Those with aphasia following stroke may have differences in experiences or challenges as highlighted by several literature reviews that have been previously conducted investigating systemic issues specifically on the experiences of stroke survivors with aphasia (see for example Ford, Douglas, & O'Halloran, 2018; Grawburg, Howe, Worrall, & Scarinci, 2012; McGurk & Kneebone, 2013).

Quantitative or mixed method designs were excluded due to the focus of the review being on the experiences and sense-making of the impact of stroke on the couple relationship, as perceived by the couple, the survivor or the partner.

**Search Strategy**

The following electronic databases were used to identify relevant articles: Medline, PsycInfo and EMBASE. The search was completed in January 2019. The search terms used can be found in Table 2. Within each category the search terms were combined with the 'OR' function and between each category using the 'AND' function. Keywords were used and adapted to each database. Additional qualitative search terms were included ("discourse*" and "discurs*" and "narrative*") to ensure that articles were captured that used narrative analysis or discourse analysis.

Table 2
*Search terms that will be used to identify articles for the systematic literature review*

| Stroke search terms | Interpersonal search terms | Couple unit search terms | Qualitative search terms |
|---|---|---|---|
| Stroke* | Relationship* | Carer* | Qualitative method* |
| Cerebral vascular accident* | Relationship status | Caregiver* | Qualitative |
| Cerebrovascular accident* | Relationship dynamic* | Spouse* | Interview* |
| CVA | Relational | Partner* | Focus group* |
| Transient isch*emic attack | Relational dynamic* | Husband* | Discourse* |
| TIA | Psychosocial | Couple* | Discurs* |
| Isch*emic stroke* | Role* | Marriage* | Narrative* |
| Isch*emia | Intimate | Wife | |
| Isch*emic | Intimacy | Wives | |
| | Interpersonal | Parent* | |
| | Coping | | |
| | Communicat* | | |

*variations in spellings of words and plurals

A scoping review was conducted as part of developing the search terms. This helped to identify search terms for the current review.

The search terms identify general relational impact rather than positive relational impact specifically. This approach was taken to systematically identify any relevant qualitative articles that explore the relational impact of stroke, including where the main focus of the article might be on negative impact of stroke on the couple relationship. The full-text screening examined whether the article discussed a positive element to the relational impact of stroke and whether the article was included.

A process of screening the reference list of included articles and the citations was conducted to identify any other potentially relevant articles not found in the original search. The articles identified were screened at the title and abstract stage.

A second-rater reviewed six studies at Phase 2 (full text screening stage) using inclusion/exclusion criteria. Inter-rater reliability was 100%.

**Quality Appraisal**

The CASP (2018) is a quality appraisal tool for qualitative data whereby the researcher assesses ten criteria, with a point awarded for each satisfied criterion. Table 3 shows the CASP ratings for each article. Each rating was considered when conducting the thematic synthesis.

The second-rater reviewed the quality of three studies included in the review. Inter-rater reliability for the CASP was 100%.

**Data Analysis**

A thematic synthesis was conducted on data collated from the thirty-two papers that made reference to the positive impact of stroke on the couple relationship (Thomas & Harden, 2008). Stage one included extracting and coding data from these articles, including quotes directly from the research participants in the articles. Stage two included generating descriptive themes consistent with the findings of the original articles. Stage three involved generating analytical themes that extend beyond the original data and examine overarching themes.

## Results

Figure 1 shows the screening process from the initial articles that were generated through Phase 1 (title and abstract) and Phase 2 (full text). 1489 articles were generated in phase 1 (346 articles from PsycInfo, 505 from Medline and 638 from EMBASE), with 1093 titles and abstracts screened after duplications.

Forward and backward chaining generated an additional 757 articles. The original search terms were narrow in order to navigate a large body of research on the experience of stroke and focus on relational aspects, capturing articles that were qualitative and referred to relational issues in the title or abstract. A large proportion of the additional articles that emerged were quantitative or articles that did not mention the relational aspects of stroke in the abstract; thus, the majority of the papers did not meet the inclusion criteria.

86 articles from the original databases were screened at phase 2, plus a further 40 articles generated from the reference lists and citations that were screened in order to reach data saturation. 32 articles met the inclusion criteria, according to the SPIDER inclusion and exclusion criteria in Table 1. Study characteristics of the articles are included in Table 3.

Figure 2

*PRISMA flow chart to show the screening process*

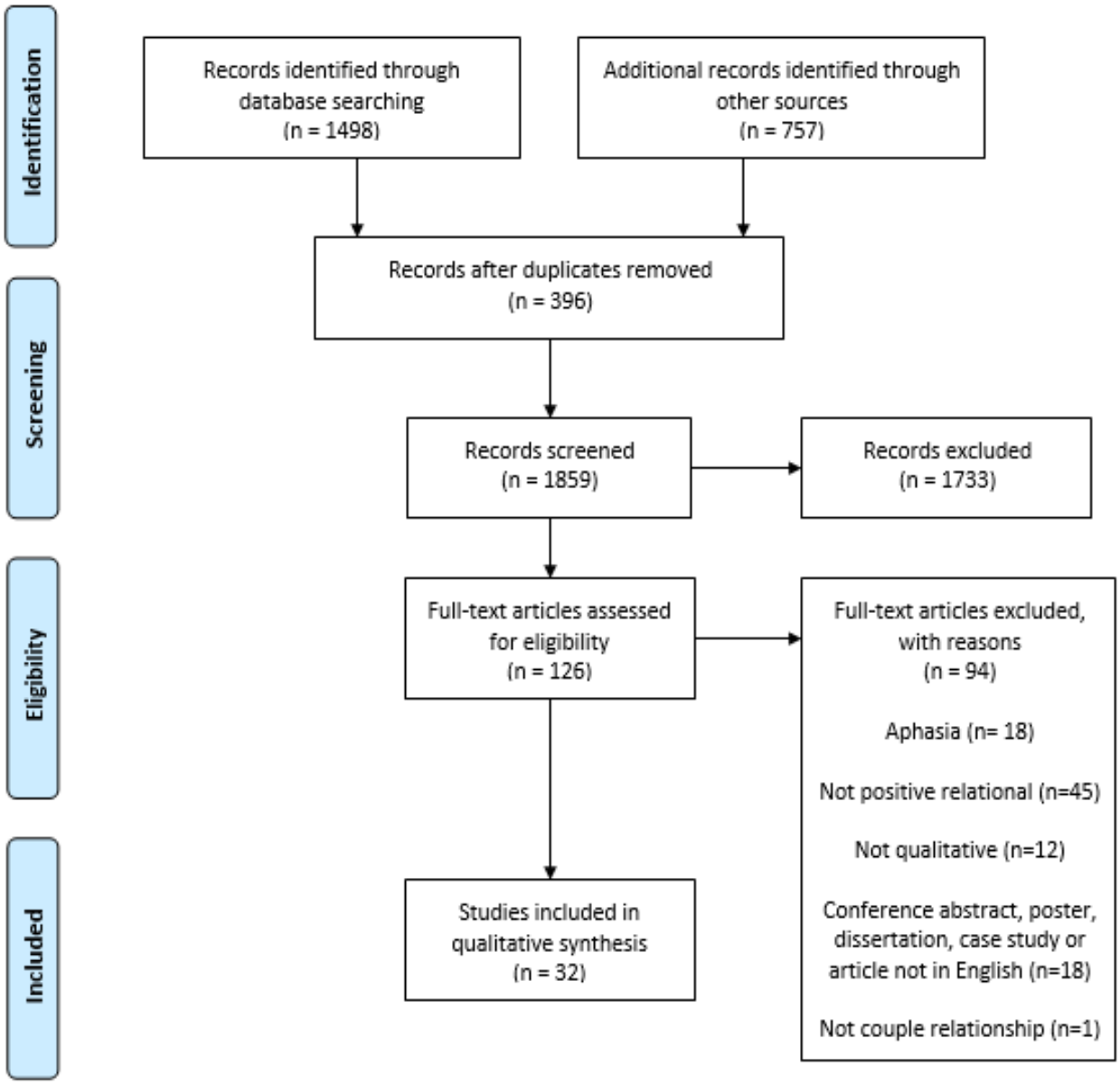

Table 3
*Summary of the characteristics of the articles evaluated in the review*.

| Author (year) Title | Aim of the research and theoretical framework | Participants, demographics of sample | Methodology | Findings related to research questions | CASP Rating, strengths and limitations |
|---|---|---|---|---|---|
| 1) Anderson et al., (2017a)<br><br>Reconciling Marriage and Care after stroke | To explore joint perspectives of couples in context of a stroke<br><br>Grounded theory | 18 couples (15 married couples, 3 separated couples)<br><br>Age range: 35-81 | Joint couple and individual semi-structured interviews<br><br>Community, discharge six months or more | Relationships were consolidated and emotional connections were re-established. Support given by spouses was appreciated. The relationship was reciprocal, with giving and receiving and teamwork. The couple spent time together and their understanding of the other increased. | 8 out of 10<br><br>Strength(s):<br>-Clear rationale for methodology<br><br>Weakness(es):<br>-Doesn't critically examine their roles as researchers<br>-No explicit consideration of validity. |
| 2)Anderson, Keating & Wilson (2017b)<br><br>Staying married after stroke: a constructivist grounded theory qualitative study | To explore the renewal or breakdown of marriages following a stroke<br><br>Grounded theory | 18 couples (15 married, 3 separated)<br><br>Age range: 35-81 | Joint couple interviews and individual semi-structured interviews<br><br>Community, six months or more following stroke | A change in communication between the couple: open communication, negotiating, resolving conflicts. Partners facilitated the survivor in feeling more capable. There was an appreciation of the support received from the partner and a valuing of the other. | 8 out of 10<br><br>Strength(s):<br>-Clear aims and methodology<br><br>Weakness(es):<br>-Does not discuss consent and confidentiality considerations<br>-No considerations for bias introduced by researcher |

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| 3) Bäckström & Sundin (2007)<br><br>The meaning of being a middle-aged close relative of a person who has suffered a stroke, 1 month after discharge from a rehabilitation clinic | To highlight the experiences of middle-age relatives of stroke survivors<br><br>Focusing on those 1 month post-discharge<br><br>Phenomenological-hermeneutic interpretation of the narratives | 10 middle-aged close relatives: 8 spouses, 1 spouse not cohabiting.<br><br>Age range: 23-58<br><br>2 males, 8 females | Narrative interviews with partners<br><br>Part of longitudinal study (1 month, 6 months, 1 year)<br><br>Community, 1 month after discharge | Remembering their love for one another was considered important, as well as holding on to the person before the stroke. Adapting to a new life together and recognising how much they had been through together. | 8 out of 10<br><br>Strength(s):<br>-Sensitive to ethical considerations<br><br>Weakness(es):<br>-No consideration for the bias introduced by the researcher. |
| 4) Bäckström & Sundin (2009)<br><br>The experience of being a middle-aged close relative of a person who has suffered a stroke, 1 year after discharge from a rehabilitation clinic: A qualitative study | To explore the experiences of those middle-age relatives of stroke survivors<br><br>Focusing on those 1-year post-discharge<br><br>Thematic content analysis | 9 middle-aged close relatives: 7 spouses, 1 not cohabiting<br><br>Age range: 41-65<br><br>2 males, 7 females | Narrative interviews with partners<br><br>Community, 1 year after discharge | The relationship brought joy and a deeper sense of togetherness. The love felt by the spouse was essential to overcome challenges presented by the stroke. | 9 out of 10<br><br>Strength(s):<br>-Consideration of bias introduced by the researcher<br><br>Weakness(es):<br>-Lack of justification for research design<br>-Bias of females in sample |

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| 5) Bäckström, Asplund, & Sundin (2010)<br><br>The meaning of middle-aged female spouses' lived experience of the relationship with a partner who has suffered a stroke, during the first-year post-discharge | To explore the impact of the couple relationship from the perspective of female middle-aged spouses whom are caring for stroke survivors one year after discharge<br><br>Phenomenological-hermeneutic method of thematic analysis | Four female middle-aged spouses of partners diagnosed with a first-time stroke<br><br>Age 40-58<br><br>Relationship lasted 8-36 years | Narrative interviews with spouses<br><br>Longitudinal over the first year following discharge (1, 6, 12 months) | 1 month after discharge, spouses were being supportive of the survivors and helping them connect to others. There was a deep togetherness in the relationships. 6 months after discharge, the couples were moving towards a reciprocal relationship and adapting to new lives together. 1 year after discharge there was a sense of closeness, love and strength, whilst the spouses were still supporting and protecting the survivor. | 10 out of 10<br><br>Strength(s):<br>-Aims, methodology, findings and discussion clear<br><br>Weakness(es):<br>-Considerations about triangulation or validation are not discussed<br>-Small sample |
| 6)Banks & Pearson (2004)<br><br>Parallel lives: Younger stroke survivors and their partners coping with crisis | To investigate the impact of stroke on the couple relationship in younger stroke survivors. Also, to explore the impact on the patient and the partner<br><br>Grounded theory | 38 younger stroke survivors and their partners<br><br>Age range: 20-49 | Longitudinal, two time points over a 9-month period<br><br>Participants asked to complete a diary in between<br><br>Community, first time point 3-6 months post-discharge | For some couples, going through the experience of stroke together had strengthened the relationship. | 4 out of 10<br><br>Strength(s):<br>-Findings clearly discussed<br><br>Weakness(es):<br>-Aims, methodology and analysis are lacking in detail |

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| 7)Cecil, Thompson, Parahoo, McCaughan (2013)<br><br>Towards an understanding of the lives of families affected by stroke: a qualitative study of home carers | To investigate the lived experience of carers of stroke survivors, including what has impacted them and explore concepts of coping and caring<br><br>Thematic analysis | 30 carers, of which 19 were spouses (15 females, 4 males)<br><br>Age range of spousal carers: 36–84 | Individual interviews with family caregivers<br><br>Community | In elderly couples, there was a recognition of each other's strengths and weaknesses. The couples supported one another. Caring for the other was seen as something that they were lucky to be able to do for their partner. | 8 out of 10<br><br>Strength(s):<br>-Thorough findings section, including consideration of rigour of results.<br><br>Weakness(es):<br>-No consideration of bias introduced by researcher |
| 8) El Masry, Mullan & Hackett (2013)<br><br>Psychosocial experiences and needs of Australian caregivers of people with stroke: prognosis messages, caregiver resilience, and relationships | To investigate the experiences of those caring for survivors of stroke, specifically focusing on psychosocial factors<br><br>Interpretative phenomenological analysis | 20 caregivers: 15 of which were spouses<br><br>10 stroke survivors: 8 of which have spouses as caregivers | Interviewed separately apart from 3 dyads<br><br>Unclear if survivors are in community or rehabilitation | Relationships were described as being supportive, and one spouse described the relationship now as "unbreakable". The new role of caregiver led to more perceived respect from a survivor. | 9 out of 10<br><br>Strength(s):<br>-Robust discussion about implications of the research<br><br>Weakness(es):<br>-No consideration of bias introduced by the researcher<br>-Lack of consistency in data collection |

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| 9) Green & King (2009)<br><br>Experiences of male patients and wife-caregivers in the first-year post-discharge following minor stroke: a descriptive qualitative study | To investigate factors that have impacted male patient and their spousal caregiver's quality of life. To also explore caregiver burden<br><br>Content analysis | 26 male patients and their wife-caregivers<br><br>Age range: 33-83 | Semi-structured individual telephone interviews 1,2,3,6,9,12 months following hospital discharge<br><br>Longitudinal<br><br>Community | Some couples valued the relationship and the other in the couple more, as there was greater appreciation in the dyad and more of a focus on the relationship. There was more time spent together, and the spouse helped to adapt activities to suit the stroke survivor. More time spent together meant more time talking and sharing. | 8 out of 10<br><br>Strength(s):<br>-Methodology clear<br><br>Weakness(es):<br>-Validity or triangulation not considered<br>-Consent and confidentiality not discussed |
| 10) Gustafsson & Bootle (2013)<br><br>Client and carer experience of transition home from inpatient stroke rehabilitation | To investigate the experience of transitioning from rehabilitation to home from the perspectives of the stroke survivors and their caregivers and their experience of being at home for the first month<br><br>Inductive thematic | Five stroke survivors and their carers: three of whom were spouses<br><br>Age range: 62-79 (excluding dyads where caregiver is not a spouse) | Interviewed separately<br><br>Community, 1 month after discharge | One survivor recognised the support of her husband, that previously she had not recognised in their relationship. Another spouse talked about how he had taken on the role of motivating his partner in everyday tasks to facilitate recovery. | 8 out of 10<br><br>Strength(s):<br>-Thorough data analysis procedure, including two researchers completing the analysis<br><br>Weakness(es):<br>-Lack of explicit consideration for the bias introduced by researchers |

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| 11) Kvigne, Kirkevold & Gjengedal (2004)<br><br>Fighting back-struggling to continue and preserve the self following stroke | To investigate the experience of life after stroke and how this was managed: from the perspective of female stroke survivors.<br><br>Giorgi (1985) phenomenological four-step method | Twenty-five women suffering first-time stroke<br><br>Age range: 37-78 | Longitudinal: interviewed three times during the first 1.5 years after stroke.<br><br>Unclear if survivors are in community or rehabilitation. | Some wives reported developing close relationships with their husbands that were collaborative in nature. Wives expressed appreciation towards their husbands for support and understanding. For some couples, activities were always done together. | 7 out of 10<br><br>Strength(s):<br>-Methodology clear<br><br>Weakness(es):<br>-Discussion is not detailed or robust enough |
| 12) Lever & Pryor (2017) The impact of stroke on female sexuality | To investigate how female sexuality is impacted following stroke<br><br>Inductive thematic analysis | 9 female stroke survivors<br><br>Age range: 31-70 | Individual semi-structured interviews<br><br>Unclear if survivors are in community or rehabilitation | Females experienced orgasm and sexual arousal following stroke. The giving and receiving of intimacy, such as kissing, cuddling, touching, holding hands, were valued by the females in their relationships. Trust was considered important for sexuality post-stroke. | 10 out of 10<br><br>Strength(s):<br>-Reflexivity and bias of the researchers explicitly considered<br>-Thorough data analysis procedure including consideration of rigour and credibility |

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| 13) Lopez-Espuela et al., (2018)<br><br>Critical points in the experience of spouse caregivers of patients who have suffered a stroke. A phenomenological interpretive study | To investigate the experiences of spouses of stroke survivors whom are caring for their partner<br><br>Thematic content analysis (Giorgi) | 18 spouses<br><br>5 males, 13 females<br><br>Age range: 42-80 | Semi-structured interviews with spouses<br><br>Unclear if survivors are in community or rehabilitation | Couples described re-building their life together. Through their joint experience, some felt they had a better understanding of their partner. Some couples had discovered new ways of communicating together and the importance of non-verbal "emotional communication". | 9 out of 10<br><br>Strength(s):<br>-Sensitive consideration of what the experience of participating might be like for spouses<br><br>Weakness(es):<br>-Lack of explicit justification for the design |
| 14) Lynch et al. (2008)<br><br>Life after stroke: social relationships | To explore factors of quality of life that are important to stroke survivors, with the aim of supporting the development of a specific quality of life measure for stroke<br><br>Thematic analysis | 9 survivors (5 men, 4 women)<br><br>Mean age 54.7 years<br><br>6 caregivers (1 man, 5 women), four caregivers were spouses<br><br>Mean age 57.2 | Focus groups, one for stroke survivors and the other for caregivers (recruited separately)<br><br>Community | Caregivers in the focus group described how the experience had strengthened the couple relationship. A survivor in the stroke group showed appreciation for how caring her spouse had been and how fortunate she was for that support. | 8 out of 10<br><br>Strength(s):<br>-Two coders were used for the analysis<br><br>Weakness(es):<br>-No consideration for the bias introduced by the researchers<br>-Bias of females in caregiver sample |

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| 15) McCarthy & Bauer (2015)<br><br>In sickness and in health: couples coping with stroke across the life span | To investigate how the experience of a stroke impacts on couples, whom are of different ages and relationship duration<br><br>Constant comparative method | 31 couples<br><br>Age range: 31-93<br><br>Stroke 1-36 months prior to the interview | Separate interviews for spouses and survivors<br><br>Unclear if survivors are in community or rehabilitation | A survivor expressed how lucky they were, whilst another couple talked about the experience bringing them closer together. One spouse expressed pride at the progress made by their spouse. Couples adapted to limitations from the impact of the stroke, together, and values and priorities were re-evaluated. | 9 out of 10<br><br>Strength(s):<br>-Discussion is very detailed<br>-Large sample size<br><br>Weakness(es):<br>-No consideration for bias introduced by the researcher<br>-Lack of diversity in sample |
| 16) Meijering, Nanninga & Lettinga (2016)<br><br>Home-making after stroke. A qualitative study among Dutch stroke survivors | To explore how stroke survivor's conceptualise home following a stroke<br><br>Inductive and deductive coding and analysis | 24 stroke survivors<br><br>45-70 years<br><br>7 months- 6.5 years after stroke | Interviews and focus groups with survivors<br><br>Significant others may be present<br><br>Community | A couple described how the couple relationship had improved as a result of the stroke. A stroke survivor talked about spending more time together, whilst another discussed how the couple were more reliant on one another and were more aware of each other's needs. | 9 out of 10<br><br>Strength(s):<br>-Method was modified and reasons explained<br><br>Weakness(es):<br>-No consideration for bias introduced by the researcher |

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| 17) Moore, Maiocco, Schmidt, Guo, & Estes (2002)<br><br>Perspectives of Caregivers of Stroke Survivors: Implications for Nursing | To explore caregiver's perspective of caring for a stroke survivor<br><br>Thematic analysis | 8 caregivers of which 5 were spousal caregivers<br><br>5 females, 3 males<br><br>30-80 years old | Semi-structured interview<br><br>Unclear if survivors are in community or rehabilitation | One spouse expressed that the experience of stroke had bought the couple closer. | 8 out of 10<br><br>Strength(s):<br>-Aims and methodology clear<br><br>Weakness(es):<br>-Lack of consideration for the bias and reflexivity of the researcher |
| 18) Nilsson, Fugl-Meyer, von Koch, & Ytterberg (2017)<br><br>Experiences of sexuality six years after stroke: a qualitative study | To investigate stroke survivor's experiences of sexuality after stroke and communication with healthcare professionals about sexuality concerns: 6 years on<br><br>Thematic analysis | 12 survivors<br><br>Age range: 43-81<br><br>Five women, seven men<br><br>Six years after stroke | Interviews with survivors<br><br>Unclear if survivors are in community or rehabilitation | Sexuality had become more positive for some couples because of an increase in other types of intimacy, for instance hugging and kissing, whilst also taking a slower pace. It was acknowledged a positive change in intimacy had led to a deepening of the couple relationship. | 9 out of 10<br><br>Strength(s):<br>-Two coders used for analysis<br><br>Weakness(es):<br>-Lack of consideration for researcher bias or reflexivity |

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| 19) Norris, Allotey, & Barrett (2012)<br><br>'It burdens me': the impact of stroke in central Aceh, Indonesia | To explore the experience of stroke in an area of Indonesia<br><br>Thematic analysis | 11 stroke survivors<br><br>Four males, seven females<br><br>Age range: 32-69<br><br>18 carers, unspecified number of spouses | Interviews and photographic facilitated interviews<br><br>Observation over a nine-month period<br><br>Longitudinal<br><br>Unclear if survivors are in community or rehabilitation | One stroke survivor described how her and her husband were more collaborative in their roles, for instance her husband had helped her with cooking. | 9 out of 10<br><br>Strength(s):<br>-Aims, methodology and findings clear<br>-Creative methods of facilitating interviews<br><br>Weakness(es):<br>-Lack of consideration for researcher bias or reflexivity |
| 20) Pierce & Steiner (2004)<br><br>What are male caregivers talking about? | To explore the experiences of male caregivers, whom engaged in an online support group, to stroke survivors<br><br>Friedmann's framework | 5 male caregivers: four of which are spouses<br><br>Aged 55-72 | Telephone surveys bimonthly. Data collected from questions asked and answered on website, and online discussions<br><br>Longitudinal, data collected between January and September<br><br>Community | Caregivers felt a connection through their experience of caring and felt it brought them closer to their wives. There was an appreciation of the value of time. | 7 out of 10<br><br>Strength(s):<br>-Methodology clear<br><br>Weakness(es):<br>-Discussion is not detailed and robust enough<br>-Small sample size |

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| 21) Pierce (2001)<br><br>Caring and Expressions of Spirituality by Urban Caregivers of People with Stroke in African American Families | To explore how spirituality can impact the experiences of caregiving, including well-being and functioning, in families whom are of African American descent<br><br>Friedmann framework | 8 primary and 16 secondary caregivers; 5 spouses<br><br>4 men, 20 women<br><br>Age range: 22-76 | Three interviews with caregivers<br><br>Observation-participation sessions with each family<br><br>Unclear if survivors are in community or rehabilitation | Caregivers expressed their love and affection for the stroke survivors. One spouse described how he loves his wife and they share everything. He also expressed how much pleasure he gets from the role of caring. | 8 out of 10<br><br>Strength(s):<br>-Bias considered and researcher kept a personal journal<br><br>Weakness(es):<br>-Lack of explicit ethical considerations<br>-Bias of women in sample. |
| 22) Pilkington (1999)<br><br>A qualitative study of life after stroke | To explore the impact on quality of life in the three months following a stroke<br><br>Parse analysis | 13 stroke survivors<br><br>9 men and 4 women<br><br>Aged 40-91 | Longitudinal<br><br>Interview whilst still in hospital, then 1 month after stroke and 3 months after stroke<br><br>Community and rehabilitation | A stroke survivor expressed that he felt fortunate to have a “good wife”. | 9 out of 10<br><br>Strength(s):<br>-Aims, methodology and analysis clear<br><br>Weakness(es):<br>-Lack of consideration for bias in researcher role |

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| 23) Robinson-Smith & Mahoney (1995)<br>Coping and Marital Equilibrium After Stroke | To explore how married couples, whom are considered older, overcome the impact of stroke and attempt to reach equilibrium in the marital relationship<br><br>Content analysis | Seven couples (four male stroke survivors, three female stroke survivors)<br><br>Age range of stroke survivors: 55-80 | Joint interviews<br><br>6-12 months since the stroke<br><br>Community<br><br>Cross-sectional | One spouse expressed that she paced her activities so that it would be OK for her husband. A survivor talked about how her husband had also had a stroke and together the merging of their strengths as a couple "make a half decent person" (page 87). | 8 out of 10<br><br>Strength(s):<br>-Validity considered in findings<br><br>Weakness(es):<br>-Lack of consideration for bias and reflexivity in the researcher |
| 24) Röding, Lindström, Malm, & Öhman (2003)<br><br>Frustrated and invisible—younger stroke patients' experiences of the rehabilitation process | To explore the stroke survivors, whom are considered younger, experience of stroke and rehabilitation.<br><br>Grounded theory | Two women and three men<br><br>Age range: 37-54 | Interviews with survivors whom had their stroke at least two years ago.<br><br>Community | A survivor expressed how tiredness, from the stroke, had affected his ability to engage in sexual relations but that him and his wife had learnt to adapt in order to overcome the difficulty. | 8 out of 10<br><br>Strength(s):<br>-Triangulation used in the analysis<br><br>Weakness(es):<br>-Small sample<br>-Lack of consideration for reflexivity of researchers<br>-Small sample size |

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| 25) Saban & Hogan (2012)<br><br>Female Caregivers of Stroke Survivors: Coping and Adapting to a Life That Once Was | To explore the lived experience of female carers to stroke survivors whom experienced their stroke in the last year<br><br>Content analysis | 46 female caregivers, of which 24 were wives<br><br>Survivor had stroke in the last 3-12 months<br><br>Age range: 18-73 | Written questionnaire asking open-ended questions<br><br>Unclear if survivors are in community or rehabilitation | A caregiver expressed that it had strengthened their relationship and lead to the couple to reconsider what was important in their lives. A caregiver also expressed that her husband was doing whatever he could to recover and that his courage gave her strength. | 9 out 10<br><br>Strength(s):<br>-Bias and reflexivity considered<br>-More than one researcher for the analysis<br>-Large sample size<br><br>Weakness(es):<br>-Design of written questionnaire may provide less rich data |
| 26) Satink et al. (2016a)<br><br>Negotiating role management through everyday activities: narratives in action of two stroke survivors and their spouses | To explore the experience of everyday activities in the context of stroke survivors, their spouses and role management<br><br>Narrative analysis, “narrative in action approach” | Two stroke survivors: Betsy (age 67) and Martin (age 68), and their spouses | Longitudinal: 3, 6, 9, 15- and 21-months post-discharge<br><br>Observations and interviews<br><br>Community | For Betsy, she negotiated with her spouse about an activity that had changed in the course of her stroke: cooking.<br><br>For Martin, his spouse enabled him to have connections with his friends. His wife stated that Martin had been supportive of her whilst she was unwell. | 9 out of 10<br><br>Strength(s):<br>-Aims, method, analysis and findings clearly explained<br><br>Weakness(es):<br>-Small sample size of two couples. |

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| 27) Satink et al. (2016b)<br><br>Self-management develops through everyday activities- a longitudinal qualitative study of stroke survivors during two years post-stroke | To investigate how individuals who had experienced a stroke managed life after discharge and what meaning they attributed to their ability to manage<br><br>The constant comparative method | 10 stroke survivors<br><br>6 females, 4 males<br><br>Age range: unspecified | Observation and interviews with survivors<br><br>Longitudinal: 3, 6, 9, 15- and 21-months post-discharge<br><br>Community | It was described how stroke survivors have learnt to co-manage alongside their partners. A participant expressed that a good balance and dialogue had been established regarding co-managing. | 8 out of 10<br>Strength(s):<br>-Multiple researchers for the analysis section<br><br>Weakness(es):<br>-Lack of consideration for researcher bias<br>-Lack of detail in justifying design of study. |
| 28) Secrest (2000)<br><br>Transformation of the Relationship: The Experience of Primary Support Persons of Stroke Survivors | To explore the quality of life and lived experience of carers of stroke survivors<br><br>Interpretative framework | 10 primary support persons of stroke survivors: 8 of whom are spouses<br><br>8 females, 2 males | Individual interviews | One spouse described feeling proud of her husband whom was a stroke survivor, whilst another spouse described how his wife, the stroke survivor was his strength. Another spouse described doing new activities together which strengthened the relationship. | 10 out of 10<br><br>Strength(s):<br>-Aims, methodology, analysis findings clear<br><br>-Discussion robust |

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| 29) Tellier, Rochette & Lefebvre (2011)<br><br>Impact of mild stroke on the quality of life of spouses | To investigate the quality of life of spouses of stroke survivors, 3 months after discharge<br><br>Thematic analysis | 8 spouses<br><br>Age range: 45-71<br><br>6 females, 2 males | Interview 3 months after discharge<br><br>Community<br><br>Cross-sectional | Two female spouses saw the stroke as a chance to become closer to the stroke survivor. A spouse expressed feeling useful and appreciated by the stroke survivor. | 7 out of 10<br><br>Strength(s):<br>-Consideration of validity of the findings<br><br>Weakness(es):<br>-Lack of information about recruitment and reflexivity of the researchers |
| 30) Torregosa, Sada, & Perez (2018)<br><br>Dealing with stroke: perspectives from stroke survivors and stroke caregivers from an underserved Hispanic community | To explore the experiences of recovery and adjustment from the perspectives of stroke survivors and caregivers in an underprivileged community<br><br>Thematic analysis | 11 stroke survivors<br><br>8 partners<br><br>Age range: 30-78<br><br>Time since stroke: 1-24 years<br><br>Mean age of survivor: 60<br>Mean age of caregiver: 53 | Individual interviews<br><br>Focus groups, separate for survivors and carers<br><br>Unclear if survivors are in community or rehabilitation | Survivors suggested the experience had bought their relationship closer. For one couple they were close to separating prior to the stroke. | 9 out of 10<br><br>Strength(s):<br>-Aims, findings and analysis clear<br>-Researcher bias discussed in relation to analysis<br><br>Weakness(es):<br>-No consideration about researcher bias in methodology<br>-Variable time since stroke |

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| 31) White et al. (2007)<br><br>Barriers and facilitators to caring for individuals with stroke in the community: The family's experience | To investigate what are perceived as barriers or facilitators to engaging with the role of caregiver to stroke survivors<br><br>Thematic analysis | 14 caregivers<br><br>The majority were over 50 and spouses<br><br>"About 50% were female" | Focus groups and interviews with caregivers<br><br>Unclear if survivors are in community or rehabilitation | A male spouse expressed that the experience had bought the couple closer together. He expressed that they were supporting one another and spent all their time together. | 9 out of 10<br><br>Strength(s):<br>-more than one researcher doing analysis<br><br>Weakness(es):<br>-lack of consideration of researcher bias<br>-lack of explicit details about research participants |
| 32) Yilmaz, Gumus, & Yilmaz (2013)<br><br>Sexual life of poststroke women with mild or no disability: a qualitative study | To explore the perspectives of women after stroke regarding their sexuality and sexual life.<br><br>Thematic analysis | 16 female stroke survivors<br><br>Age: over 18 | Interviews with survivors<br><br>Unclear if survivors are in community or rehabilitation | A woman with a right temporal parietal lesion reported an improvement in her sex life and feelings of love towards her husband as if they were just married. | 8 out of 10<br><br>Strength(s):<br>-Methodology and aims clear<br><br>Weakness(es):<br>-Discussion lacking in detail and robustness |

## Characteristics of Included Studies

The aims, methodology, data analysis and inclusion and exclusion criteria for participants varied across the articles; however, all the studies used a qualitative design. The qualitative methodologies used were thematic analysis (5, 7, 10, 12, 14, 17, 18, 19, 29, 30, 31, 32), grounded theory (1, 2, 6, 15, 16, 24, 27), content analysis (9, 23, 25), thematic content analysis (4, 13), narrative analysis (26), interpretative phenomenological analysis (8), phenomenological data analysis (11), phenomenological hermeutic interpretation of narratives (3) and existential-phenomenological approach (28). Three studies were not clear in the specific qualitative methodology used (20, 21, 22); however, two of the articles referred to themes but not in relation to a specific method (21, 22).

Ten studies were longitudinal (3, 5, 6, 9, 11, 19, 20, 22, 26, 27). The majority of data was collected through interviews (1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 15, 16, 17, 18, 19, 21, 22, 23, 24, 26, 27, 28, 29, 30, 31, 32); however, data was also collected using focus groups (14, 16, 30, 31), observations (19, 26, 27), surveys (20), questionnaires (25) and participants keeping a diary (6).

The focus of the research was on stroke survivors only (11, 12, 16, 18, 22, 24, 27, 32), relatives or caregivers only (3, 4, 5, 7, 13, 17, 20, 21, 25, 28, 29, 31) or both survivors and caregivers (1, 2, 6, 8, 9, 10, 14, 15, 19, 23, 24, 30). Sample sizes ranged from 4-62 participants and age of participants ranged from 20-93 years of age.

The articles were from United States of America (14, 15, 17, 20, 21, 23, 25, 28, 30), Canada (1, 2, 9, 22, 29, 31), Australia (8, 10, 12), Malaysia (19) and Europe: Sweden (3, 4, 5, 24), Netherlands (16, 26, 27), United Kingdom (6, 7, 19), Norway (11), Turkey (32) and Spain (13).

**Quality appraisal results**. The article by Banks and Pearson (2004) was deemed as ‘poor’ on the CASP rating. The methodology and data analysis were considered to be lacking in detail and ethical considerations were not explicit. Regarding the findings in the article, the data was coded into a descriptive theme that contained data extracted from eleven studies (‘strengthening existing relationship’); therefore, it was not necessary to make alterations to the thematic synthesis as a result of the quality appraisal of this article.

The overall quality of the remaining articles was good with ratings ranging from 7 (Kvigne et al., 2004; Pierce & Steiner, 2004; Tellier et al., 2011) to 10 (Bäckström et al., 2010; Lever & Pryor, 2017; Secrest 2000). A large proportion of articles lacked consideration for the researcher-participant relationship and the impact of bias upon the methodology, analysis and interpretation of the research (question six and eight in the CASP checklist).

## Thematic Synthesis of Results

A thematic synthesis generated three analytical themes which encompass ten descriptive themes. The three analytical themes identified were: ‘strengthening of the couple bond’, ‘enhanced ways of relating’ and ‘empowerment by the spousal caregiver’. The process from coding to analytical themes can be visualised in Table 4.

Table 4

*Coding, descriptive themes and analytical themes in thematic synthesis*

| Step 1: Coding | Step 2: Descriptive themes | Step 3: Analytical themes |
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| 88 codes across 32 articles. | Strengthening existing relationship. | Strengthening of the couple bond. |
| | Deeper understanding of the other or the self. | |
| | Greater appreciation of the other. | |
| | Re-evaluation of priorities. | |
| | Greater sense of reciprocity. | |
| | Improved communication. | Enhanced ways of relating. |
| | Enhanced sexual, physical and emotional intimacy. | |
| | More time spent together. | |
| | Empowering and motivating the stroke survivor. | Empowerment by the spousal caregiver. |
| | Protecting the stroke survivor. | |

## Strengthening of the Couple Bond

This first analytical theme encompassed five descriptive themes: ‘strengthening existing relationship’, ‘deeper understanding of the other or the self’, ‘greater appreciation of the other’, ‘re-evaluation of priorities’ and ‘greater sense of reciprocity’. This theme encompasses a deepening bond between the dyad: an appreciation, a deeper understanding and a more cohesive sense of togetherness. An element of vulnerability was highlighted, the concept that oneself is exposed and allows oneself to be dependent on the other in the dyad. This was along with a sense that the relationship is reciprocal, irrespective of the stroke survivor or carer role, and that both parties benefit from support by the other. The literature encompassed a newly awakened value in the relationship between the couple, which prior to the stroke may have been lost. Despite the challenges the couples faced, positive emotions were described using words such as “joy” (Bäckström & Sundin, 2009), “affection” (Lopez-Espuela et al., 2018), “perfect” (Anderson et al., 2017b) “love” and “peace” (Pierce, 2001). The relationship itself was described as “rock solid” (Anderson et al., 2017b) and “unbreakable” (El Masry et al., 2013).

**Strengthening existing relationship.** Eleven studies described a strengthening of the bond between the dyad as couples identified that the stroke, and living through the experience of recovery from stroke, enhanced the existing couple relationship. In some circumstances this meant resolution of marital conflict: “the stoke bonded us together…we were on the verge of splitting up” (Torregosa et al., 2017), whilst in other instances it reaffirmed the pre-stroke relationships: “old relationships were reconfirmed, or changed relationships were acknowledged and accepted” (Anderson et al., 2017b).

There was an acknowledgement that the couple had experienced something challenging, together, and this had strengthened the couple relationship (Banks & Pearson, 2004; Lopez-Espuela et al., 2018). Within one article, it was described as “our union has deepened, we’ve grown closer, closer in our sadness” (Lopez-Espuela et al., 2018). One article reported “two women mentioned an opportunity to be closer to the client with stroke” (Tellier, 2011).

**Deeper understanding of the other or self.** Three studies described a deeper understanding of the other or self through the joint experience of stroke. Desire to learn about the other in the context of stroke (Anderson et al., 2017a; Anderson et al., 2017b) seemed to facilitate a greater understanding of the other person and “reaching new understandings of their husband and wife roles” (Anderson et al., 2017b). Lopez-Espuela and colleagues (2018) described this deeper understanding as “knowing the essence of the other” in the couple relationship. For example, Anderson and colleagues (2017b) outlined how a spouse developed a robust understanding of the survivor in the context of their recovery, and that this enabled him to assist and empower the survivor’s learning about themselves as a stroke survivor: “that was [spouse] that bought multi-tasking to my attention. He was the one that was mindful of it for me”.

**Greater appreciation of the other.** Twelve studies described a greater appreciation of the other through the experience of stroke. Appreciation was noted in the context of caring for the other or in the courage shown by the survivor, which led to a greater appreciation of the other in the couple dyad (Green & King, 2009). Appreciation was reciprocal in the couple dyad: “we sit there on the couch and hold hands and think how lucky we are” (McCarthy & Bauer, 2015).

There was also a recognition that the couple had experienced something together and had managed to “create a new life with one another” (Bäckström & Sundin, 2007). A wife acknowledged that her partner, the stroke survivor, was showing courage in how he had managed the experience of stroke and his recovery: “my husband is doing everything he possibly can do to get better” (Saban & Hogan, 2012) and expressed pride in the survivor’s recovery (McCarthy & Bauer, 2015; Secrest 2000). There was a common perception by survivors of their spouses as “caring”, “kind”, “loving”, “patient” and “understanding”. This seemed to instil an attitude of gratitude towards the spouse in which the survivors felt fortunate for their support (Kvigne et al., 2004; Lynch et al., 2008; Pilkington, 1999). Survivors identified their spouse as the “one person that was there” but also, compared to other significant people in their lives, the support they received from their spouse had been more beneficial (Anderson et al., 2017a; Anderson et al., 2017b).

**Re-evaluation of priorities.** Five studies described a re-evaluation of priorities. There was a sense that the experience of stroke had led couples to “put life in perspective” in that they reconsidered what was valuable and important in their life, including their couple relationship (Green & King, 2009). One couple spoke about “how valuable time really is” (Pierce & Steiner, 2004), whilst others shared thoughts about how lucky they were and “also made us re-evaluate our values” (McCarthy & Bauer, 2015). This re-evaluation of priorities seemed to allow the couple to acknowledge and accept how much their spouse cared about them and the appreciation for their relationship (Anderson et al., 2017b).

**Greater sense of reciprocity.** Nine articles highlighted that couples may experience a greater sense of reciprocity which was experienced as a

supportive and positive change in the couple relationship (Satink et al., 2016a). Bäckström and Sundin (2010) described this concept as: the "relationship to their partner melded together in a symbiotic way". There was an understanding that this reciprocity had emerged from having to work through new challenges together (Anderson et al., 2017b; Satink et al., 2016a) and as a result being more reliant on one another: "we rely more on each other" (Meijering et al., 2016). The increase in reciprocity was at times associated with a process of re-creating the marriage, as discussed by Anderson and colleagues (2017b).

Irrespective of the role of stroke survivor and carer, both members of the couple felt valuable in the couple dyad. One spouse described how his wife, whom had had the stroke, "was his strength" (Secrest, 2000). Cecil and colleagues (2012) noted that with older couples, both members of the couple dyads had their strengths and weaknesses so worked together in supporting one another: "so who is looking after whom?" This was reiterated in other articles: "…together we make a half decent person" (Robinson-Smith & Mahoney, 1995) and "we help one another" (White et al., 2007). There was a wider acknowledgement of being sensitive to each other's needs (Meijering et al., 2015), despite whom was the stroke survivor in the couple dyad. For one couple, 6 months after discharge, there was a move away from the role of carer and stroke survivor to a reciprocal couple relationship: "we have each other and now we must try to pull together" (Bäckström et al., 2010).

**Enhanced Ways of Relating**

The second analytical theme encompassed three descriptive themes: 'improved communication', 'enhanced sexual, physical and emotional intimacy' and 'more time spent together'. This analytical theme refers to the processes by which the couple relate in a loving and tender way as they navigated through

the challenges of experiencing a stroke. It links to the first analytical theme of strengthening of the couple bond. Descriptive themes within this overarching theme could be considered mechanisms or processes to facilitate the strengthening of the couple bond. This theme incorporated the sensitivity and adaptability emerging within the couple dyad, in the ways that couples communicated verbally, were intimate, and spent time together.

**Improved communication.** Four articles acknowledged an improvement in the communication style of the couple as a result of stroke. Experiencing stroke and the rehabilitation that followed, led some couples to communicate more effectively about their problems: “learned to talk about our problems” (Anderson et al., 2017b). As well as “affording them the opportunity to “talk more openly” (Green & King, 2009), there was also an acknowledgement that the communication between couples was more empathic and compassionate in nature (Lopez-Espuela et al., 2018).

Negotiation was a key part of the couple adapting to the new challenges they faced following stroke (Satink, 2016b), as well as making sense of their new identities as individuals and as a couple through disagreements which were in fact considered “veiled negotiations” (Anderson, 2017b). It makes the suggestion that communication between the couple was constructive in adapting to the couple’s new life post-stroke.

**Enhanced sexual, physical and emotional intimacy.** Six articles highlighted that for some couples the stroke enhanced emotional, sexual and physical intimacy. Sexual intimacy was improved through the couples being flexible in their approach to intimacy: “he and his wife had found ways to have a functional sexual life despite the problem” (Roding et al., 2003) and finding new ways to show affection within the couple relationship. For some, this involved

being more loving, slower-paced and tender, through means such as hugging, kissing and caressing (Nilsson et al., 2017; Lopez-Espuela et al., 2018). It was described that some couples found “strength in moments of closeness” (Bäckström et al., 2010) suggestive of the power of physical and emotional intimacy, whilst Lever and Pryor (2017) explored the importance of female stroke survivors experiencing close intimate relationships and how these were established through caring and being cared for, and through the reciprocal nature of intimacy: “sharing, caring, and feeling cared about through giving and receiving intimacy were hallmarks of a close intimate relationship”. A balance between sexual intimacy and other types of intimacy are valued: “it has got a sexual part as well as the loving and caring parts” (Lever & Pryor, 2017).

Yilmaz and colleagues (2013) reported a woman with a specific ischemic lesion in the temporo-parietal area whom experienced heightened sexual pleasure. The researchers linked the findings to other literature reporting hypersexuality in those with neurological insult in the temporal lobe. Another study reported individuals who “experienced sexual desire, arousal and orgasm post stroke” (Lever & Pryor, 2017).

This current theme links with the descriptive theme ‘improved communication’ as intimacy assisted communication; for example, checking-in with the other through touch alone: “it is a very feeling-oriented, emotional type of communication” (Lopez-Espuela et al., 2018).

**More time spent together.** Eight articles discussed how couples were spending more time together . In some cases, time spent together involved adapting activities they enjoyed previously (McCarthy & Bauer, 2015). For example, one spousal carer reported slowing the pace of the activity to ensure it was at an appropriate pace for the stroke survivor, and making other

adaptations to the time spent together as a couple (see for example Robinson-Smith & Mahoney, 1995). In other cases, more time spent together was facilitated by discovering new joint interests (McCarthy & Bauer, 2015; Norris et al., 2012; Secrest, 2000). Discovering and engaging in new activities together gave the couple a greater sense of connection with each other and increased satisfaction with their new life, despite an increase in responsibilities: “these activities brought them closer together, resulting in a “satisfying life”” (Secrest, 2000), particularly as it allowed them time to focus on their relationship (Green & King, 2009).

### Empowerment by the Spousal Caregiver

The final analytical theme encompasses two descriptive themes: ‘empowering and motivating the stroke survivor’ and ‘protecting the stroke survivor’. This theme refers to the position of the spouse to the stroke survivor, perhaps in a role of caregiver. It could be interpreted that the power imbalance between the stroke survivor and the spouse could be used by the spouse in a facilitative manner: through protection, defending and acting as a motivator and “informal therapist” (Gustafsson & Bootle, 2013).

**Empowering and motivating the stroke survivor**. Five articles identified that spouses can empower the stroke survivor in a position of “motivator or informal therapist” (Gustafsson & Bootle, 2013). A sense of empowerment appeared through facilitating social interaction with significant others (Anderson et al., 2017b; Bäckström et al., 2010; Satink et al., 2016b) or helping to challenge the spouse with everyday activities. For example, making everyday activities harder as it was perceived to be in the best interest of the recovery of the stroke survivor (Green & King, 2009; Gustafsson & Bootle, 2013); for instance, “I know I’m leaving a bit more to her [stroke survivor] all the

time, but that is planned by me to get to see if she can do little bit more" (Gustafsson & Bootle, 2013).

**Protecting the stroke survivor.** Two papers identified a role of the spouse in protecting the stroke survivors. Bäckström and colleagues (2010) described spouses in a position of protecting their spouses, sometimes 'carrying' their spouses and sometimes "defended the image of their partners held by others" as the stroke had caused others to view the stroke survivor differently. Green and King (2009) described a spouse who attempted to re-frame the survivor's perceived role within the family following the stroke, by reassuring the stroke survivor of their value in the family.

## Discussion

A systematic search of the qualitative literature on experiences of stroke identified thirty-two articles that explore aspects of the positive impact of stroke on the couple relationship. Thematic synthesis revealed three overarching themes: ‘strengthening of the couple bond’, ‘enhanced ways of relating’ and ‘empowerment by the spousal caregiver’. The findings highlight that despite challenges in experience of stroke there is the possibility for couples to display resilience and build upon their strengths as a couple to enhance their relationship, even to the extent of experiencing growth and joy within the couple dyad despite facing adversity (Bäckström & Sundin, 2009).

The findings of the current review fit well within the systemic model of dyadic coping (Bodenmann, 2005). Positive dyadic coping is divided into two strands: common dyadic coping, which involves the couple jointly supporting one another in the relationship in times of stress, and supportive dyadic coping, which involves one partner taking on more of a supportive role to manage the stress for the couple. The concept of common dyadic coping can be seen within the first two analytical themes: ‘strengthening of the couple bond’ and ‘enhanced ways of relating’. Within these two analytical themes, the couple are showing a resilience and strength in their bond that helps them to manage the adversity they are facing. The couples are also adapting the ways in which they relate in order to improve their capacity to cope as a couple. The concept of supportive dyadic coping is demonstrated in the final analytical theme: ‘empowerment by the spousal caregiver’ as the spouse takes on the role of motivator and protector to facilitate coping of the couple dyad. The findings suggest that couples adopt these dyadic coping strategies as part of enhancing the couple relationship through the experience of stroke.

Bodenmann (2005) highlights that positive dyadic coping can enhance feelings of togetherness. Meanwhile, the current findings also utilised the concept of common dyadic coping to understand the analytical theme of 'strengthening the couple bond' and descriptive themes of: 'greater sense of reciprocity', 'strengthening the existing relationship' and 'deepened understanding of the other or the self'. The model of dyadic coping, as conceptualised by Bodenmann (2005; Figure 1), is a linear relationship whereby dyadic coping can strengthen the couple relationship. However, the findings of this study go beyond this by highlighting how the act of strengthening and enhancing the couple relationship leads to further dyadic coping. For instance, the results suggest couples may engage in greater reciprocity and that the "relationship to their partner melded together in a symbiotic way" (Backstrom & Sundin, 2010) which is an enhancement of Common Dyadic Coping. This implies a cyclical dynamic in which dyadic coping strengthens the relationship which triggers further dyadic coping. Future research should go beyond the mechanism of dyadic coping and examine the impact of dyadic coping on the couple and how it feeds back into dyadic coping and how this may facilitate rehabilitation. Observations of couples in stroke rehabilitation could be utilised in this respect.

**Implications for Rehabilitation**

Rehabilitation can play an important role in supporting families to live well with stroke as the findings show the protective element of dyadic coping for the couple. For example, the findings have identified that spouses can be protective and motivational (Bäckström et al., 2010; Gustafsson & Bootle, 2013), couples can show adaptation through their engagement in intimacy or communication (Lopez-Espuela et al., 2018; Roding et al., 2003) and can experience a sense of

reciprocal value and appreciation from the other in the relationship (Green & King, 2009; Satink et al., 2016a). These factors, amongst others identified, are likely to facilitate recovery.

There is a need for rehabilitation staff to be aware of the positive impact of stroke on the couple relationship, most notably the theory behind dyadic coping and the benefits it can have for the couple. This could be a training requirement for rehabilitation staff facilitated by the clinical psychology team in the rehabilitation setting. As part of this training, rehabilitation staff could be trained on how to recognise and assess premorbid strengths of the couple. The aim of training would be for staff to facilitate the couple to connect with strengths post-stroke and to monitor these strengths throughout the journey of stroke rehabilitation and in the community. Aspects of strength and resilience observed could be fed back to the couple to empower further dyadic coping.

Rehabilitation settings should create regular opportunities for couples to reflect on the positive impact of stroke on their relationship as it is important for dyads to be able to communicate all aspects of their stroke experience, positive or negative. The findings also suggest the importance of rehabilitation staff talking about sexuality and intimacy within stroke rehabilitation, as the results showed a large proportion of papers talking about this topic (Lever & Pryor, 2017; Nilsson et al., 2017; Röding et al., 2003; Yilmaz et al., 2013). This supports the observation that rehabilitation clinicians show reluctance to address the topic of sexuality (McGrath et al., 2019). These conversations give permission to couples to explore other ways of being intimate, such as closeness and touch, rather than sexual intimacy which may have been negatively affected (Nilsson et al., 2017).

In cases where the couple are exhibiting little or no dyadic coping rehabilitation staff could signpost to appropriate services for relational support. The majority of the research provides evidence that the experience of stroke for couples is challenging to manage and the current review did not explore the needs of couples that are struggling to the extent of needing professional support. However, the current findings remain relevant to clinical psychologists working with couples who require psychotherapy post-stroke. Psychological intervention could be in the form of systemic couples' therapy, with the aim of facilitating improved and adapted styles of communication, better understanding of the other in the couple dyad and discussion about difficult aspects of the relationship such as intimacy. It may be that discussions, within this safe and non-judgemental space, may facilitate the couple in identifying with some of the descriptive themes identified in the current review. For example, one of the findings in the current review was the concept of reciprocity. Couples need to be encouraged to re-engage with a reciprocal relationship whereby the stroke survivor and spouse are both giving and receiving (White et al., 2007). Therapeutic intervention may motivate the stroke survivor in recognising their ability to still be able to give, move away from the role of patient and thus feel valued in their intimate relationship as a partner.

The current findings suggest that stroke may lead couples to go through a process of re-evaluating their priorities. In this respect, a therapeutic model such as Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 2011) may be beneficial to assist the couple in re-visiting their values. Couples may need assistance in reconnecting with the value of relationships.

**Critical appraisal.** The current review offers an alternative perspective to the dominant narrative in the qualitative stroke literature and fills a gap in the

current empirical literature as identified by Lou and colleagues (2017). It also makes a unique contribution to informing rehabilitation practice.

The review attempted to identify all published qualitative literature that highlighted the positive impact of stroke on the couple relationship. Studies were included if the content of the article contained as little as a sentence on the positive impact of stroke on the couple relationship. However, the full text was only read if the abstract mentioned the impact on the couple of experiencing a stroke; therefore, there may be articles containing elements of this topic area which were not included because the abstract did not mention the couple relationship.

A second limitation of this review is the exclusion of studies that included patients with aphasia as stroke survivors with aphasia may represent up to 40% of the stroke population (Denier, 2016). If these papers had been included this may have enhanced the theme about ‘improved communication’ and may have given insight into how rehabilitation can facilitate improved communication amongst couples. Thus, the current findings may not be representative of the general stroke population including those affected by aphasia and would require further exploration.

It is important to consider that the analytical theme ‘empowerment by the spousal caregiver’ is comparatively weak compared to the other analytical themes. The theme contains two descriptive themes which themselves contain less data compared to the other themes discussed. An interpretation of this is that the current articles generated do not capture the essence of this theme fully and would be enhanced with a sole focus on caregiving. However, the theme was included due to the richness of the data (all articles rated ‘8’ and above on

the CASP rating) and what it adds to our understanding of the couple dyad. Further research on caregiving could seek to further understand the concept of empowerment, protection and motivation by the spousal caregiver.

The current review may be generalisable to how couples experiencing other neurological or long-term health conditions face adversity in a positive manner, as research has shown the construct of dyadic coping is applicable to couple's experiences of health and illness in many different contexts. For example, the findings may be relevant to couples where one person in the dyad has an acquired brain injury or may be particularly useful for those conditions where there is a limited evidence base for the couple's experience; for example, brain tumour.

The review by Ostwald (2008) reported no papers that investigated interventions for couples. Future research should explicitly investigate how the strengths of couple's post stroke links to rehabilitation interventions by using long-term outcomes of well-being of the survivor and spouse, and evaluation measures that examine the perceived strength of the couple dynamic. The methodological quality of future qualitative research could be improved by researchers reporting their critical reflections, biases or assumptions.

## Conclusion

The current review identified thirty-two articles that explore the perceived positive impact that can emerge between couples in the context of stroke. A thematic synthesis identified ten descriptive and three analytical themes that describe the resilience shown by the couple dyad in the face of this adversity. The analytical themes include a 'strengthening of the couple bond', 'enhanced ways of relating' and 'empowerment by the spousal caregiver'. This review

provides implications for rehabilitation staff who can empower couples in recognising and engaging in their strengths as a couple. The review also provides implications for couples who are struggling to engage with dyadic coping and offers suggestions for clinical and systemic interventions. Future research should focus on how these interventions can be introduced into clinical practice in stroke rehabilitation with evaluation of the potential long-term benefits for couples.

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**Appendix A:** Instructions for authors submitting an article to Disability and Rehabilitation

We encourage authors to be aware of standardised reporting guidelines below when preparing their manuscripts:

- Case reports - CARE
- Diagnostic accuracy - STARD
- Observational studies - STROBE
- Randomized controlled trial - CONSORT
- Systematic reviews, meta-analyses - PRISMA

Whilst the use of such guidelines is supported, due to the multi-disciplinary nature of the Journal, it is not compulsory.

**Structure**

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form,

with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

**Word count**

Please include a word count for your paper. There is no word limit for papers submitted to this journal, but succinct and well-constructed papers are preferred.

**Style guidelines**

Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use any spelling consistently throughout your manuscript.

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

For tables and figures, the usual statistical conventions should be used.

**References**

Please use this reference guide when preparing your paper. An EndNote output style is also available to assist you.

**Checklist: what to include**

6. **Author details**. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) requirements for authorship is included as an author of your paper. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

7. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.

8. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.

9. 5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

10. A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:

*Example 1: Leprosy*

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

*Example 2: Multiple Sclerosis*

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

11. **Acknowledgement**. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was

supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .

12. **Declaration of Interest**. This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a declaration of interest and how to disclose it.

13. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.

14. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.

15. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.

16. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.

17. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

18. **Equations**. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.

19. **Units.** Please use SI units (non-italicized).

**Consent**

All authors are required to follow the ICMJE requirements on privacy and informed consent from patients and study participants. Please confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any research, experiment, or clinical trial described in your paper has given written consent to the inclusion of material pertaining to themselves, that they acknowledge that they cannot be identified via the paper; and that you have fully anonymized them. Where someone is deceased, please ensure you have written consent from the family or estate. Authors may use this Patient Consent Form, which should be completed, saved, and sent to the journal if requested.


**SCHOOL OF PSYCHOLOGY**

**DOCTORATE IN CLINICAL PSYCHOLOGY**

**EMPIRICAL PAPER**

# The construction of couple relational dynamics, roles and intimacy in talk about living with malignant brain tumour: a discourse analysis.

Trainee Name: **Siobhan Betts**

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Secondary Research Supervisor: **Dr Janet Smithson**

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Target Journal: Neuro-Oncology

Word Count: 8428 words (excluding abstract, table of contents, list of figures, references, footnotes, appendices)

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**Abstract**

*Objectives:* To explore the impact of relational dynamics on couples impacted by malignant brain tumour, with the aim of expanding the knowledge we have about the impact of brain tumour from the perspective of the patient, carer and couple. The current research gives a different perspective of the relational impact of this illness through use of discourse analysis and joint interviews.

*Methods:* Six heterosexual couples took part in the research which involved conducting joint semi-structured interviews with the couple in their homes. The interviews were analysed using a discourse analysis approach to observe how the couples constructed meaning about their shared experience of a brain tumour and its impact on the couple relationship.

*Results:* Couples used rhetorical strategies, such as humour and deflection, to ease discomfort and navigate the sensitive topic. Discourses used by both partners highlights that the journey can be one of isolation, despite the presence of a partner. In contradiction, the couple were often positioned together, against the brain tumour itself, in a position of dyadic coping.

*Conclusions:* Conversations about the impact of brain tumour are highly sensitive. As a result, couples implement strategies in order to communicate their difficulties, their distress and challenging elements such as death and uncertainty of the future. Clinical implications are offered for how health care professionals facilitate discussions between couples and how the dynamic between a couple can be supported in hospitals, rehabilitation and in the community.

*Keywords*: Malignant Brain Tumour, Couples, Relational Dynamics, Discourse Analysis

*Importance of the Study:*

The study enhances what is already known about the experiences of couples who are living with malignant brain tumour by utilising a novel methodological approach: discourse analysis. This methodology allows us to examine moment-by-moment interactions with the couple that may capture how couples navigate and negotiate their roles and relationship dynamic within the adverse context of brain tumour. The findings may be beneficial to a range of healthcare professionals working with the couples impacted by brain tumour. The theoretical disposition of discourse analysis fits to that of systemic practice; thus, the current study provides implications for psychology and systemic practice.

## Introduction

Malignant brain tumours make up 3% of new cancer cases each year in the United Kingdom (UK), with 11,432 new cases of brain tumour in 2015 (Cancer Research UK, n.d.). The survival rates have doubled in the past forty years, with 3 in 20 individuals diagnosed with brain tumour living beyond ten years post-diagnosis (Cancer Research UK, n.d.). The progress of the illness is typically defined as ‘early-treatment’, ‘post-treatment’ and ‘end-of-life’, when treatment is no longer considered effective for managing the brain tumour growth (Boele, Grant, & Sherwood, 2017). Each phase may bring new challenges for the brain tumour survivor and the system around the individual.

Individuals with a brain tumour present with different symptoms and difficulties depending on the location of the tumour(s) in the brain, the stage of the tumour(s) and the presence of swelling or intra-cranial pressure (Cancer Research UK, 2015). Patients report motor, sensory and visual deficits, as well as difficulty with cognition and language (Behin, Hoang-Xuan, Carpentier, & Delattr, 2003). Several known factors mediate psychological functioning: presence of cognitive decline or fatigue, the journey of treatment, and previous or current mental health difficulties (Baker, Bambrough, Fox, & Kyle, 2016). Research highlights a decline in psychological-wellbeing with disease progression (Cavers et al., 2012).

Caregivers of individuals with a brain tumour have been described as a “unique subset of caregivers” by Sherwood and colleagues (2004) due to the complexity of the symptoms and the potentially short trajectory of the illness. Sherwood and colleagues (2004) attempted to conceptualise the stress response for caregivers in a model which shows the relationship between the brain tumour and the caregivers internal and external resources. The impact

and burden of caring for a significant other with a malignant brain tumour has been acknowledged by National Institute for Health and Care Excellence (NICE) guidelines (2006). It is recommended that the well-being of the carer and family should be a consideration throughout the illness. A systematic literature review by Madsen and Poulsen (2011) identified themes of anxiety amongst carers, as well as a lack of information about how to manage the role of daily caregiving in the community.

The research on the impact of brain tumour strongly suggests the need for support for both patients and caregivers. The impact on the couple relationship also requires consideration by researchers and clinicians.

## Brain tumour and Systemic Understanding

**Theory of systemic impact of illness.** There has much research dedicated to investigating how couples and families face adversity in the context of illness. This current research will be embedded in systemic theory to contextualise couples' experiences and coping.

Firstly, dyadic coping is the process of coping as a dyad, rather than alone, and can improve functioning within the relationship (Traa, De Vries, Bodenmann, & Den Oudsten, 2015). If a couple perceive the stressor of illness to be something that should be managed as a couple they will be more inclined to use active coping strategies such as open communication (Altschuler, 2015), which has been identified as a protective factor against stressful events in the couple as well as the family (Henry, Sheffield Morris, & Harrist, 2015).

In addition, the Family Distress Model (Cornille & Boroto, 1992; Figure 1), is a model driven by systemic ideas and family therapy.

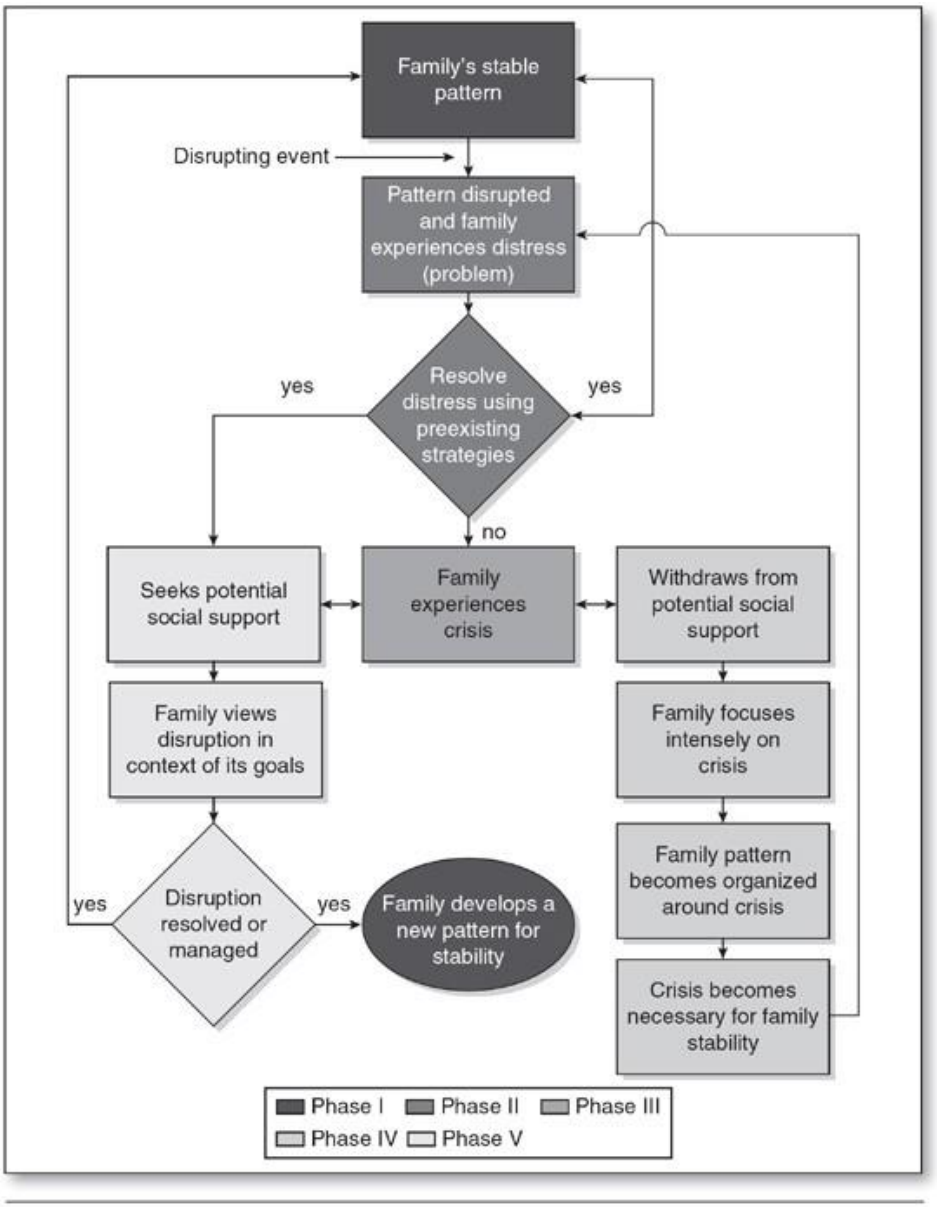


Figure 1: *Family Distress Model (Cornille & Boroto, 1992)*

The model argues that families have familiar patterns that ensure stability in the unit. When there is an event that threatens to destabilise the family unit, the model outlines alternative strategies that may be implemented when a family reaches a crisis and are no longer able to utilise previous strategies. For example, instead of seeking support they may instead withdraw from support.

The model describes different phases of a family attempting to reach stability through crisis and can be used, particularly in family interventions by the clinician, to identify the family's position in managing the crisis or their distress. For instance, a clinician may identify that a family are in the process of generating new strategies to establish a new stable position and may identify another family are organising themselves around the crisis in order to create stability. The clinician can then tailor the intervention to the position the family unit are in. The model is grounded in social constructivist position; therefore, is interested in the families understanding of their problems, which plays an important part of the intervention process.

**Impact of brain tumour on couple dyads.** Sterckx and colleagues (2013) conducted a systematic literature review on the impact of living with a brain tumour on daily life, from the perspective of the carer and patient. Within this review couple dynamics were discussed; for example, changes in roles between couple dyads were identified and how these roles evolved as the disease progressed. Spouses may feel a sense of responsibility for their partner and may take on a protective role to ensure the survival of their partner (Strang & Strang, 2001). Some couples find adaptation following diagnosis challenging and have to generate novel ways of adapting (Lovely et al., 2013). Communication between couples affected by brain tumour has been explored through separate interviews with couples across the course of the disease (Salander & Spetz, 2002). In some instances, both partners had awareness of the seriousness of the situation; however, were unable to communicate their concerns with one another, leading to a distancing between the dyad.

The empirical literature on the relational dynamics within a couple affected by brain tumour is limited so requires further exploration. Sterckx and

colleagues (2013) recommend that research should focus on the impact of living with a brain tumour on relationships, specifically from the patients' perspectives. They advocate for a dyadic approach to care and the need for health care professionals to recognise and understand the impact on couples and how to support them. Empirical literature has mainly conducted interviews separately with couples, focusing on the perspective of the patient or the caregiver. The research has neglected to capture the couple perspective on the changes in relational dynamics, including roles, communication and intimacy, between the couple as a result of a brain tumour.

**Discourse Analysis**

Discourse analysis (DA) takes a social constructionist perspective to qualitative data, suggestive that reality is constructed within a specific social context (Edwards & Potter, 2001; Potter & Wetherell, 1987). The focus of DA is on the 'linguistic practice' of interaction as language is used as an action and function, rather than language being an interpretation of one's internal states (Potter & Wetherell, 1987). Discourses are constructed and constructive: they are constructed through language and construct a version of an object or ideological dimension in that moment and context. Discourses are also action-orientated and situated: language is a platform for social action and has to be understood in the context of what else is spoken, how it is spoken and the context in which it is spoken (Wiggins & Potter, 2007).

There have been no research papers identified using DA as an approach to capturing the joint construction of the experience of brain tumour. Morris (2001) critically examines the use of joint and individual interviews with cancer patients and carers, concluding that joint interviews enrich data compared to

individual interviews. DA has been an analytical approach that has enhanced the cancer, health and palliative literature; furthermore, DA has enhanced the political and social context of health and illness discourses that goes beyond the content of conversations about health (Lupton, 1992). DA has been used in the cancer and palliative literature to capture patient's experience of illness and dying: the understanding of how cancer patients construct the concept of hope in the face of death (Elliot & Olver, 2009) and discourses about acceptance or denial of dying as identified by Zimmerman (2012). Relational elements of the impact of illness have been explored using DA: for instance, the construct of sex after cancer (Ussher et al., 2013).

The Family Distress Model (Cornille & Boroto, 1992) is socially constructivist in its theoretical underpinnings, which compliments the social constructionist nature of DA. The model is grounded in the understanding and appraisal that the family construct their current context and that interventions should be focused upon this. Use of DA in the context of this current research, improves our understanding of how couple's make sense of their context. It could also give an insight into how couples talk with healthcare professionals, in hospital, rehabilitation or community, as couples were aware of my role as a staff member of the National Health Service (NHS).

### Aim of Study

The aim was to better understand the impact of brain tumour on the couple dyad. The research question was: **'**what discourses are constructed in couples' conversations about living with a brain tumour?'

## Method

### Ethics

The research was granted ethical approval by the University of Exeter Ethics Committee on the 12th June 2018. Amendments were made during the research (see Appendix A).

## Design

The research used a qualitative methodology. Data collection involved semi-structured interviews with couples.

**Participants.** Twelve participants were recruited using a convenience sampling method. Couples were all heterosexual and married. The individual with the brain tumour was in treatment or post-treatment phase (Boele et al., 2017).

***Inclusion and exclusion criteria.*** Individuals who had a malignant brain tumour and their spouses were included. Participants were over eighteen and both members had to be keen to participate.

The inclusion of individuals with cognitive, communication or physical difficulties was promoted and this was explored with the patient or partner. Participants were encouraged that adaptations would be made, if required. Individuals with profound expressive or receptive language impairment, who may struggle to articulate experiences within an interview, were excluded.

Participants were also excluded if the patient was deceased, the participant was not in an intimate relationship or the relationship with the patient was not a spousal relationship. Furthermore, participants were excluded if there was evidence of a current mental health or physical health difficulties that may benefit from accessing appropriate services.

Table 1 provides demographic information. Each participant has been given a pseudonym.

Table 1

*Demographic information on participants*

| Couple | Ages | Type of brain tumour | Location of tumour | Status of treatment at time of appointment |
|---|---|---|---|---|
| Luke | Patient: 48 | Grade 3 oligoastrocytoma | Frontal lobe | Palliative care |
| Chloe | Spouse: Unknown | | | |
| Tara | Patient: 53 | Grade 3 anaplastic oligodendroglioma | Frontal lobe | No current treatment |
| Paul | Spouse: 56 | | | |
| Jeff | Patient: 68 | Grade 4 glioblastoma multiforme | Frontal/Parietal lobe | No current treatment |
| Pam | Spouse: 67 | | | |
| Tony | Patient: 52 | Grade 3 anaplastic astrocytoma | Frontal lobe | No current treatment |
| Lucy | Spouse: 52 | | | |
| Anna | Patient: 29 | Grade 2 glioma | Temporal lobe | No current treatment |
| Scott | Spouse: 27 | | | |
| Bill | Patient: 49 | Grade 3 anaplastic oligodendroglioma | Insula, temporal and | Undergoing |
| Louise | Spouse: Unknown | | frontal | radiotherapy. |

***Recruitment strategy.*** Contact was made with the Chief Executive Officer (CEO) of a national brain tumour charity. The Support Service Quality Assurance Officer facilitated communication with support workers across eight UK counties, who disseminated the recruitment poster through email contact lists or to support groups (Appendix B). Support workers disseminated the poster which was also posted on a closed Facebook group for the charity.

Twenty-one couples or individuals made enquiries. Six couples met the inclusion criteria and consented to be interviewed. The reasons for exclusion and drop-outs can be found in Appendix C.

## Procedure

The initial stage was to seek consultation from a couple who had shown interest in the research to receive feedback on the information sheet, consent form and interview schedule (Appendices D-F). This couple were not participants in the study.

The interview schedule was piloted with two trainee clinical psychologists.

Couples showed interest over email or telephone and the research was discussed. Eligibility was assessed during initial contact with the couple. An appointment letter (Appendix G), information sheet and consent form were posted to the couple's address.

Couples were given the choice of where to conduct the meeting; all couples chose to meet at home. During the initial meeting with the couple the Patient Health Questionnaire (PHQ-9; Kroenke & Spitzer, 2002) was completed and consent forms signed. If the PHQ-9 highlighted psychological distress in the

patient or partner, or distress was exhibited in the meeting, the participant's general practitioner was contacted with their consent. Interviews were conducted between October 2018 and January 2019. The interview length ranged from 52 minutes to 1 hour 50 minutes and were an average of 1 hour 17 minutes. Interviews were audio-recorded and transcribed by the researcher or a university approved external organisation.

Couples were offered a debrief meeting to discuss how they found the experience and to signpost to support services where appropriate.

**Method of Analysis**

The qualitative approach used to analyse the data was discourse analysis (Edwards & Potter, 1992; Potter & Wetherell, 1987). The seven steps to completing a discourse analysis, outlined by Wiggins and Potter (2007) were followed:

1: Identifying an appropriate research question

2: Identifying means of accessing or gathering data and obtaining ethical consent

3: Collecting the data

4: Transcribing the data

5: Coding the transcripts

6 Analysing the data

7: Considering application of the data and practical implications

At step 4, the transcripts utilised Jefferson's (2004) transcription method (see Appendix H). At step 6, the transcripts were analysed using the levels of

data analysis proposed by Georgaca and Avdi (2012). Two aspects emerged and were used to analyse the data: functionality of language and positioning. Level 2 (language as functional) includes how the couple use language, such as use of rhetorical devices, to facilitate action. This level of discourse analysis, according to Georgaca and Avdi, also examines what strategies individuals are using to enhance the credibility of their discourse within a conversation and the impact this has on the couple conversation.

Level 3 (positioning) includes the positioning of the object of brain tumour and the role of carer and patient. Positioning is seen as functional. Positioning is also interested in how individuals use discourses and discursive strategies to construct different identities within the conversation. Positioning may consider factors within a discourse such as who is speaking when, whom the speech is addressed to, pronouns used within speech and how the individual or couple construct speech in relation to wider discourses.

I completed a reflective log and supervisors were utilised to enhance reflexivity. Attendance at a university-based Discourse Analysis group was utilised to share data and analysis with other DA researchers.

The extracts I selected for the analysis demonstrated discourses that were emerging more widely in the data. Coyle (1995) suggested that extracts should be selected that display the array of common strategies utilised in discussing the topic.

## Analysis

Two aspects of Georgaca and Avdi's (2012) levels were used to examine how couples construct the object of brain tumour and the impact of brain tumour on their couple relationship. These levels were used interchangeably within each extract as there were many different discursive elements utilised by the couples and captured in each extract. Each extract in the analysis section draws upon more than one level or discourse; thus, the section is not organised by level or salient discourse.

In the extracts I have used 'R' to reference myself as primary researcher.

**Extract 1.** The following extract is taken from the interview with Jeff (patient) and Pam (partner).[1] Prior to this extract, the couple were talking about an oncology appointment they attended.

[1] All names in the extracts have been changed for the purpose of confidentiality.

R: it sounds like it has been a difficult (.) [year and a bit for you

Jeff: it has] been more difficult for Pam (.) than it has for me

Pam: (.) he is more positive than I am (.) although I keep thinking of all the (0.5) I've gotta try and keep telling myself (0.5) alright, I tell myself he's positive, he's doing well but then I try and keep in the back of my mind, that what's the next stage and when it going to happen (0.5) Because we don't know, you know, somebody will turn the switch on one day. (.) So I sort of try and keep, I can't say I keep a balance between the two because it doesn't work does it? ((laughter)) but umm (0.5) but yeah, I mean I go to a carer's meeting once a month now, just for a cup of tea and a chat. I say I try to go to an art class, but that's every, once a fortnight and then umm I have been to a couple of [*charity*] groups, there's one in [*town*] and one in [*city*]. Umm but at the moment, I am making cards and that, I am doing a little craft fair

Jeff: a big one

R: oh lovely

Pam: in a village a couple of miles away. So, but I'm doing that for [*charity*], they sent me a few bits of pieces. I sort of try to do that, that'll be the next thing, but I am wary about going out and leaving him on his own but (.) On his scooter I don't mind, because I know if he goes on his scooter and falls off someone will pick him up but um

Jeff: would have to be two [somebodies

Pam: yeah] ((laughter)) but I'm out, if I go out and if I know he is at home, and I think oh he could be out in the conservatory, flat on the floor

As a response to the researcher empathising with the difficulties the couple have faced, Jeff replies: “it has] been more difficult for Pam (.) than it has for me” (line 108). The function of this reply could be interpreted as an invitation for Pam to discuss her experiences as a partner and carer. With this action, Jeff is utilising his power as a patient in this conversation in a facilitative manner and in the same essence, minimising his own needs.

Pam takes up this invitation; however, she struggles to find the words to say how difficult it is: “I keep thinking of all the (0.5) I’ve gotta try and keep telling myself (0.5) alright, I tell myself he’s positive” (line 109). Pam’s struggle and discomfort at verbalising her difficulties as a carer can be seen within the discourse: use of repetition (lines 109-113), laughter (line 115) and then shifting the subject of her narrative to a safe topic (lines 115-120). From line 115, there appears to have been a shift in the flow of the discourse for Pam as she talks freely about her experiences of receiving support and engaging in hobbies. Pam then shifts the discourse back to worries, however, these are practical worries rather than emotional. The flow of Pam’s discourse here is more fluid in comparison (line 123).

Pam refers to the uncertainty of the future: “what’s the next stage and when it going to happen?” (line 112). The use of questions without answers is indicative of Pam’s uncertainty. Pam utilises a metaphor of a switch being turned on to construct talk about something bad happening (line 113) as the use of metaphor is less emotive than verbalising the raw emotion of the possibility of the situation.

Pam uses the word “positive” when referring to Jeff (line 109, 111), which might highlight that a common discourse for Jeff is one of positivity. This is supported in Jeff’s use of the rhetorical device of humour (line 128) which

serves to neutralise the emotional content of the discussion further, perhaps mirroring Pam's discomfort at talking about difficulties that have an emotional-focus rather than practical-focus. Pam acknowledges Jeff's humour with a "yeah" and a laugh (line 129), but then returns to talk about her worries about leaving him alone.

Extract 1 examines Pam's discomfort at constructing a discourse of the difficulties they have faced, and still face, despite it being invited by Jeff. It highlights the rhetorical strategies used by both members of the couple dyad in negotiating this sensitive topic.

**Extract 2.** This is from the discussion with Tara (patient) and Paul (partner), two-thirds of the way through the interview. Prior to this extract, they were talking about their experience of other professionals and the manner in which these other professionals had spoken to them.

Paul: the-ther-there was a guy in [*city*], where, as part of the [*charity*] discussions, we just sort realised, he sort of tells people probably what they want to hear in terms of good news when it's not always good news and that kind of thing.

Tara: which is fine if you're that style

Paul: yeah [yeah,

Tara: some people are that personality style.

Paul: yeah] yeah

Tara: But I like you putting the whole lot on the table, I'll look at all the worst bits and think ok now I know and I'll put it to the side and make the most of what I've got, [so I need to know the worst

Paul: open the door] and go through the door of this is the darkest situation it might be. But then you'll come back out again and shut the door. Whereas we struggled because you were going through that door and actually, I didn't want to go through that door I was looking at what is the best, what's the best it can, best or realistic situation it might be. Well let's not go there, because that's a might happen rather a probably will happen at this stage so we don't need to go there [now

Tara: yeah]

Paul: that created tensions for us, didn't it?

The discussion about the construct of the relational dynamic is elicited through the external use of a health care professional who “sort of tells people what they want to hear in terms of good news” (line 621). This leads on to Tara describing how she would benefit from “you putting the whole lot on the table, I’ll look at all the worst bits” (line 628). The description used by Tara objectifies the brain tumour into something that can be examined and then “ok now I know and I’ll put it to the side” (line 629). This discursive strategy externalises the brain tumour from Tara, the patient, using of the word “it” to describe the brain tumour, so the brain tumour can be voluntarily examined and discarded.

Paul mirrors Tara’s use of objectifying the illness as a construct you can touch and examine, introducing a metaphor of opening a door to the “darkest situation it might be” (line 631). However, the cohesiveness of the discourse shifts when he describes not wanting to go through the door whilst Tara was already “going through that door” (line 633). The use of metaphors in this extract helps the couple to express their differences of how much they can approach the realities of the illness. Paul integrates the following phrases: “we struggled” (line 633) and “created tensions for us, didn’t it?” (line 639), to introduce an emotional element into this struggle between patient and carer as to how much they want to know about the brain tumour; however, use of the pronouns “we” and “us” suggest that despite their differences they are constructing a shared experience of Tara’s illness. Furthermore, both of the phrases are in the past tense, which could be acknowledged as a function of language to neutralise this potentially threatening statement to the couple equilibrium.

Extract 3 is about a brain tumour group for carers and patients.

Paul: What was interesting there was that they had one session where they separated us, and the people with care were able to talk among themselves about what the challenges were and that kind of thing, and then you guys were able to talk about the carers.

Tara: well they asked us would you like to know how the carers feel (0.5)

R: yeah

Tara: and we all said no (0.5) no we wouldn't (0.5) and so, they'd ask, why wouldn't you like to know how the carers feel. (0.5) and it was because we knew (0.5), we already felt burdens, and we didn't want to know, they need to tell someone else it, not us. And then they asked umm (0.5) do you want your carer to (0.5) be positive and upbeat? and we said no (0.5), and they said Oh why is that? and they obviously knew the answers. And we said because we need someone to be in the dark place with us, does that make sense?

R: mmm

Tara: And then come out again together. So, when someone says you'll be alright, you can do it. Which is great when you want encouragement but when you are in that dark ((sound)), which you do go into it, whether you like it or not, it bites you in the bum. You want to be with someone in it (.) Umm and so, the carers were like oh, we thought our role was to always be upbeat, say ah you're, that's right you don't need to worry about that. And everyone was like no, that's not what we really want. So, it was a real eye opener for everybody, wasn't it?

Paul: it was, it was. And umm from the carers point of view, it's the other, we feel that as carers it's our role to be upbeat, it's our role to try and provide some balance and perspective

This scenario provides the couple with a platform to discuss something potentially dangerous to the dyad: how carers support the patient. Paul's language in this section, "they separated us" (line 645), with the use of the collective pronoun "us" referring to the couple dyad, and "then you guys were able to talk about the carers" (line 648) suggests he felt powerless as he was positioned away from Tara; this may represent his role as caregiver being reliant on the reciprocal role of 'patient' being in existence.

However, Tara offers a different discourse as she uses the collective pronoun "us" and "we" to reference brain tumour patients (line 649, 651), positioned against "the carers" (line 649), including Paul. This part of the extract shows the shared patient identities, in contrast to the couple joint identity construction, and emphasises the separate roles, experiences and identities of the patients and caregivers. Part of this experience of being a patient was explored by Tara here: the concept of feeling like a burden (line 653). When Tara constructs this discourse, there are many pauses, which could be interpreted as Tara struggling with the emotional content or showing hesitancy for how the discourse may be interpreted by Paul.

The positioning in line 657 shifts as there is a collective use of "us" by Tara to refer to the group of brain tumour survivors: "be in the dark place with us". The shift in positioning is mirrored in Paul's use of "we", referring to the group of carers, when discussing the carers perspective on this topic: "we feel…it's our role to be upbeat" (line 668). The positioning here is an example of the couple negotiating the roles of the patient and carer, and how this is distinct from the couple dyad through their separate experiences.

**Extract 4** is taken from the interview with Tony (patient) and Lucy (partner). Prior to this extract, Tony was discussing his journey of diagnosis and treatment so far.

R: Well thank you for sharing your journey with me (inaudible). Okay so, would you say your relationship has changed, kind of in the different stages of living with a brain tumour, so in [terms of

Lucy: Yes, definitely].

Tony: Yes.

Lucy: Yes, it has.

R: In what ways would you say it's changed?

Lucy: umm, its more, I feel more of a carer now than a couple(.) umm, we don't have the intimacy or the loving relationship(.) Obviously, we love each other, but things aren't as they were (.)

R: yeah

Lucy: Yes. It has changed quite a lot, hasn't it? (0.5) But we are still there for each other. The thing is I think it's nearly always knowing that something could happen and you just never know what's going to happen or how long you've got together. We are living on that sort of knife edge. (inaudible) As a couple it's very difficult.

The extract begins with consensus between the couple that living with a brain tumour has changed the couple relationship, through a repetition of the word “yes” in response to the researcher’s question (lines 69- 73). This mechanism of stance taking is known as alignment, through use of stance markers ‘yes’ (Du Bois, 2007) and is the couple positioning themselves alongside one another.

Lucy is the first to offer evidence that the relationship has changed. She states she feels more a “carer now than a couple” (line 77): whilst carer refers to a single entity, couple is a dyad. Lucy is constructing a discourse of loneliness in her role, reinforced through the perceived lack of reciprocity in the couple dyad as expressed in the next phrase: “we don’t have the intimacy or the loving relationship” (line 77). Despite these statements, Lucy shows ambivalent positioning as the discourse of a negative impact of the brain tumour on the couple dynamic is interlaced with phrases such as “we love each other” (line 78) and “are still there for each other” (line 83). Lucy seems unable to commit to the discourse of negativity and challenge. She then uses a metaphor and the cohesive “we” to represent the impact on the relationship in a safer and more collaborative standpoint: “we are living on that sort of knife edge” (line 86). This demonstrates changes in the relationship post-diagnosis and also the difficulty of talking about this with the patient, whose illness has impacted the dyad.

Lucy refers to the concept of the uncertainty of time: “you just never know what’s going to happen or how long you’ve got together” (line 85).

Tony: And umm it's trying to make lemonade without lemons and what it is, is what it is. I know the dynamics of the marriage has changed and I try to be affectionate and try to be as easy going as I can, but obviously the frustration is there and I can't do what I could and (.) DIY takes four or five times as long and it's frustrating because umm I try not to take it out on Lucy, but I do, not physically, but umm I'm quite short and [umm.

Lucy: Grumpy] ((laughter)).

Tony: Sorry ((laughter)). I try not to be.

Lucy: Victor Meldrew I call him ((laughter))

Later in the extract, Tony discusses the positive elements of brain tumour in comparison to other cancers, and uses the phrase “making lemonade without lemons” (line 118). This is a play on the phrase “if life gives you lemons, make lemonade”, this manipulation of the phrase could be interpreted as feeling hopeless, but disguising a grave situation with a light-heartened statement: masking his emotion.

Tony goes on to agree with the discourse constructed by Lucy that “I know the dynamics of the marriage has changed” (line 119). He continues with a list of what he tries to do to rectify the situation: “try to be affectionate”, “try to be as easy going as I can”, “try not to take it out on Lucy” (line 119-122). Within this discourse he uses the word “frustrating” (line 122) which is possibly a reflection of the present moment as he is using short, sharp phrases in this part of the extract.

Lucy’s response to Tony is one of using humour to neutralise the situation and unite the couple once again. Within this technique, she highlights their strategy of humour as a coping strategy between the couple: “Victor Meldrew I call him” (line 129).

**Extract 6.** The current extract is from the interview with Anna (patient) and Scott (carer). Before the extract the researcher asked whether the couple think the brain tumour has had an impact of their relationship.

Scott: I think in ways it's brought us closer (.)

Anna: yeah

Scott: as in (0.5) I think we are, say, more emotionally (0.5)

Anna: [like together

Scott: closer], would you say?

Anna: Yeah.

Scott: Like we are more of a solid team. I mean, I had quite a bad accident. Ever since then really and then this, you getting diagnosed has brought us probably even more closer.

Anna: Mmm. But like with intimacy and stuff, it's sort of decreased that (0.5)

R: mmm

Anna: ummm yeah

Scott: And understanding each other as well, sometimes I've (.) As much as I understand that it's not easy living with it, sometimes when I get in from work, I'm tired. In a selfish kind of way, I'm tired and I've been at work all day and I can't be doing with the snapping my head off sort of thing and it's trying to find that balance, it's trying to understand what the wife's going through (.) and then you [understanding that

Anna: Inaudible

Scott: I've] been at work. It's quite difficult because I'm physically tired and you're mentally tired [and

Anna: yeah] it's like I think like sometimes as well it's hard to (0.5) like, you sort of feel a bit of, I dunno (0.5)

Scott: [resentment

Anna: like resentment], because obviously he gets to go out to work and stuff as well. I miss that so much.

Scott reframes the neutral question into a positive reply. On line 96, he states “I think in ways it’s bought us closer”. Confirmation and collaboration are constructed as Anna fills the short gap left by Scott: “like together” (line 99) and Scott replies confirming “closer” (line 100). Scott then uses the phrase “solid team” (line 102) as if the couple are impenetrable and collaborative. The use of the word “team” suggests a sense of being positioned against an opposing team, which may be representative of the challenge by the brain tumour to the integrity of the couple. Scott then refers back to an example in the relationship when there was a positive shift in the relationship, when he experienced a “bad accident” (line 102), to consolidate his argument that the “team” can defeat the current difficulties.

Anna then replies with “yes, but”, and goes on to mention that intimacy between the couple has reduced (line 105). The content of this statement is deflected and taken up as an invitation by Scott to talk about a negative aspect of how the brain tumour has impacted the relationship on line 108, which between line 96-104 he might not have felt able to, perhaps due to his position as carer.

Within the paragraph (lines 108-113) Scott repeats the word “tired” within this paragraph, almost to emphasise his position as caregiver in the couple dyad and the strain it puts on him day to day. However, the language he uses suggests a feeling of guilt towards acknowledging this difficulty: “in a selfish kind of way I’m tired” (line 110), “what the wife’s going through” (line 112) and “you’re mentally tired” (line 116).

Anna hesitantly tries to introduce the emotion in her experience of the impact of brain tumour on her life. Scott offers Anna the word “resentment” (line

119) as a response to Anna's hesitation to label the emotion, which she accepts. This invitation by Scott to name the difficult emotion allows Anna the freedom to explore the emotional discourse related to being a patient and feeling resentment towards her partner. Throughout the extract, Anna and Scott both appear reluctant to say difficult emotions and cushion difficult statements with phrases such as "sort of" and "I think sometimes as well…" (line 117, Anna). However, they both appear to position themselves in a facilitative position to the other.

The following extract (7) is further into the conversation when the researcher has asked the couple if they have learnt new ways to support one another.

Scott: And because I don't speak about it.

Anna: Yes, that's the other thing, because you shut off and don't face up to it I sort of feel a bit on my own with it sometimes and then I feel like (.) because obviously it's one of those invisible illness things, isn't it, you look fine to everyone else, everyone else treats me normal or(.) which I want to be treated normal but some days I want someone to just be like, do you need to go and rest? like and I don't really get that from anyone because I just sort of plough on and (.) And it's hard in that sense as well because I put a face on it all the time. And like even with you, I said this to you the other day, don't I, he's like I don't know when you need me, because I just put a face on all the time. Because he's been at work, I feel guilty saying, I'm really, really tired, like I've had enough. So (.) it's hard (.) It's hard to find the right balance.

Scott and Anna use the word “it” to reference the brain tumour (line 268 and 270) which is a mechanism of detachment. Also, the use of the reference “it” externalises the brain tumour from Anna, the patient, positioning the brain tumour away from the individual or the couple dyad and into the position of the ‘other’, similar to Paul and Tara in extract 2.

However, Anna then describes how she feels alone in her experience of being a brain tumour survivor: “feel a bit on my own” (line 271) and “it’s one of those invisible illness things” (line 272), isolated in her role as patient. She adds the word “sometimes” on to the phrase “feel a bit on my own” which could be a mechanism of reducing the emotional impact of her words on her partner. She describes how she wants the experience of brain tumour to be shared and recognises: “everyone else treats me normal” (line 273). Anna uses the rhetorical strategy of metaphors when she describes that she “put a face on” (line 276). This could be interpreted as hiding her true experiences of being a patient; however, it is not specified who she is hiding this from.

In line 280, Anna states she is “really, really tired”. Here Anna has positioned herself along an affective scale of tiredness (Du Bois, 2007) and this is in contrast to the previous section of the extract where Scott describes himself as “tired” (lines 108-113). She uses the phrase “plough on” (line 276) which suggests the physical effort it takes to continue but the duty she has as a young parent who is also a brain tumour survivor. The repetition of “it’s hard” (line 276, 280) is confirmatory of this struggle.

**Extract 8.** The following extract is taking from the interview with Luke (patient) and Chloe (carer). Before this extract, Chloe was talking about how

Luke didn’t worry about things and Luke asked Chloe directly whether she felt stressed about the situation, of which she answered “yes”.

Chloe: we are still in that transition of learning as I said, because we've had you (0.5) dying for so long

R: mmm

Chloe: we haven't learnt how to live (.)

Luke: yeah

Chloe: and that is what I am desperately trying to do at the moment.

Luke: well [maybe we

Chloe: still try] and make memories for both of us,

Luke: yeah

Chloe: but it's hard to for Luke, the fatigue and he just doesn't want to do it. So, I've still got that element of why am I? you know(.) but then if this goes on for another five years. I don't want - to waste five years where I could have [had

Luke: (inaudible)

Chloe: him do stuff].

Chloe describes that as a couple they are in a state of “transition of learning” (line 539) and “haven’t learnt how to live” (line 542). The language used by Chloe suggests an element of hope. She uses the collaborative pronoun “we” to suggest the journey is one of collaboration and joint learning.

Chloe also utilises the collaborative “we” pronoun when describing “we’ve had you (…) dying for so long” (line 539), which suggests that Luke being in palliative care for a prolonged time has been a dyadic stressor. Chloe’s pause before the word “dying” suggests the rawness of articulating this reality.

There is a shift of pronouns in Chloe’s discourse when she starts using the pronoun “I”: “that is what I am desperately trying to do” (line 544), “I don’t want to – waste five years” (line 550), “I could have had –((interruption))- him do stuff” (line 550). The subject position of the discourse appears to shift from couple to Chloe’s position as a caregiver and there is power emerging through Chloe’s role as caregiver. Chloe appears to use her power as a protector and motivator to Luke, with a sense that it is her responsibility for him to “live” again, despite the struggles within this role: “the fatigue and he just doesn’t want to do it” (line 548).

## Discussion

The research question proposed at the start of the research was: ‘what discourses are constructed in couples’ conversations about living with a brain tumour?’

In this analysis I have shown some of the ways in which couples negotiate difficult discussions about brain tumours, mortality and the impact of these changes on the couple relationship. A range of discursive strategies were adopted to minimise, neutralise and overcome discomfort and difficult emotions

evoked by conversations with couples. Whilst prior studies have highlighted the difficulties in communication between couples impacted by brain tumour (Salander & Spetz, 2002), the current study develops this by highlighting, in the exact moments of interaction, the strategies which participants draw on to manage these difficulties within the dyad. Furthermore, the methodology of DA to capture the couple's construction of brain tumour links to the theoretical standpoint of systemic therapy and facilitates links between research and clinical work (Tseliou & Borcsa, 2018), providing a clear rationale for making links to clinical implications for therapeutic input.

The current study supports the model of FDM as it highlights how couples overcome stressors, particularly through the use of discursive strategies, which is one example of the many different approaches utilised by couples or families. The findings suggest the model could be extended or revised to recognise the power of talk in couples and families navigating crises in order to re-establish stability, as this may underpin the emergence of other strategies and approaches utilised.

Specific strategies located in the couple conversations shown here included positive discourses, avoidance strategies, objectification of the brain tumour and positioning within the dyad.

A specific coping strategy used was positive discourses. This included positive talk and the use of humour, highlighted both within the conversation and reference to the use of humour as a part of everyday communication. Lovely and colleagues (2013) identified humour and positive attitude as an internal coping strategy.

Avoidance strategies were also utilised during couple conversation, potentially due to the difficulty in having conversations about the seriousness of the situation (Salander & Spetz, 2002). To facilitate difficult conversations the couples utilised metaphors (Wodak & Meyer, 2009). Within the analysis the use of metaphors emerged during conversations that may have been threatening to the stability of the dyad, for instance negotiating roles, or during conversations about the threatening nature of brain tumour to the mortality of themselves or their partners. During periods of heightened emotion in the conversations, shifts towards more practical problems were observed. Another strategy was the objectification and 'othering' of the brain tumour, as couples constructed the disease as "it" and described it as something that could be examined and then shut away. This mechanism permitted discussion about the disease to be more manageable.

Part of my analytical focus was on positioning within the couple dyad. Couples often used the collective "we" assuming a joint experience of the tumour. This union through joint experience may position the couple against the tumour; in this respect, the disease is seen as a dyadic stressor that should be collaboratively navigated (Bodenmann, 2005). Alternatively, there was sometimes rupture of the dyad with separate positioning, through the use of "I" as a cancer survivor versus "I" as a carer. This links with the discourse of isolation that emerged, irrespective of role of survivor or carer, confirming research by Lovely and colleagues (2013). The sense of "I" was enhanced with the use of the "us" position, through a shared group of patients or carers. This links to the pattern of the dyad seeking social support if the resources within the family are limited in that context and moment (Family Distress Model; Cornille & Boroto, 1995). The shift between these positions within the couple

conversations highlights difficulties of negotiating these positions and expands upon the understanding that roles evolve during the process of living with a tumour (Sterckx et al., 2013). The language used highlights transitioning and learning, suggestive that part of the process of coping with the illness is through adapting, supported by the Family Distress Model (Cornille & Boroto, 1995).

## Reflective Considerations

Reflexivity was an important part of this research. I chose to research the area of brain tumour as I have experienced the impact of this disease personally. Thus, I utilised supervision to manage the emotional element of the research and to recognise where this may impact on conducting and interpreting the research. Supervision was imperative when a participant passed away during the data collection phase.

My role as a qualitative researcher had to be explored, in relation to the contrasts of being a clinician. It was important to recognise the differences here. I recognised in some interviews, I was being positioned as a clinician through being asked clinical advice and I had to manage this as a researcher, not a clinician.

## Clinical Practice Implications

The research has implications for health care professionals, including clinical psychologists, who may work with patients and partners in an oncology health setting, neurological rehabilitation setting or in systemic therapeutic practice. However, it is important to note the limitations imposed by service provision. The NICE guidelines (2006) acknowledge the need for assessing psychological wellbeing but do not provide recommendations for the course of action if there are concerns regarding the patient or partner's well-being. The

current findings show the importance for couples and families to be able to access appropriate support; however, the lack of concrete recommendations may reflect a gap in service provision for couples and families accessing oncology psychology services. Furthermore, access to psychological services may only be for those with “more severe distress”, despite it being considered of great importance by patients (National Health Service, 2000). Thus, it is hard to translate guidelines and findings from research studies into clinical practice so there is a need for clinical implications to be manageable and feasible.

The research highlights the discourses that may emerge in a health setting when discussing challenging and sensitive topics with patients with a brain tumour, and their partners. There is the potential that clinicians may miss the needs of the individual and their partner due to the subtle discursive strategies used by couples in the presence of health care professionals. Couples may focus on practical worries and show an avoidance for the emotional element of their experience. Healthcare professionals can assist in exploring this with couples in a safe manner.

Systemic therapy could play a pivotal role in facilitating conversations between couples. Firstly, the current findings suggest that couples may struggle to negotiate their role as a member of the couple dyad or the caregiver or survivor. Systemic therapy could facilitate the conversation about individual roles in the couple dyad and how to unite the couple (Bodenmann, 2005). Systemic practice and rehabilitation should engage couples in recognising the benefits of facing the experience of brain tumour collaboratively, as supported by the model of dyadic coping.

Secondly, the Family Distress Model (Cornille & Boroto, 1995) states that in systemic practice, clinicians should focus on understanding the appraisal the family makes about a problem. Clinicians can enhance their understanding of the couple's appraisal by considering the discursive strategies identified in the current research which will assist in providing effective interventions for couples.

Finally, the Family Distress Model also identifies that families can become organised around the stressor, in this case the brain tumour, which enables the stressor to hold power within the family context. The language used by couples to talk about illness can be influential for the family and potentially pathologising (Rolland, 2018). However, it can have the opposite effect as seen in the discursive strategies used in the current research; for example, the use of the word "it" to describe the brain tumour.

**Critical Appraisal**

The current research has provided couples with an opportunity to collaboratively explore the experience of living with a brain tumour. It has enhanced the field of research by utilising a method of analysis that links theoretically to family therapy in practice.

The sample size was relatively small as the brain tumour population is hard to recruit and there were many reasons for exclusion. Whilst each patient was screened to ensure they could verbalise their experiences, there may have been some loss of cognitive and communicative ability which will have impacted the couple's discourse and resulting analysis. In addition, participants were recruited from a charity; therefore, this naturally biases the sample to those who are willing to seek out support. Another limitation was including patients in both the post-treatment and treatment phase. It could be hypothesised that the

reflexive capacity of these individuals and couples were different between these stages.

It is important to acknowledge this research has focused on couples impacted by malignant brain tumour; however, future research could examine the impact of benign brain tumour on families.

Future research should focus on couples accessing systemic therapy for couples impacted by brain tumour, and evaluate intervention outcomes in order to provide clearer guidelines on the evidence base for couples affected by brain tumour and shape neurorehabilitation and oncology services.

## Conclusion

This research has added to the literature on experiences of patients and their spousal caregivers, through the use of a novel analysis for this field of research: DA. This method has provided insight into how couple's construct discussion about brain tumour in joint interviews. Use of avoidance strategies emerged in couples' conversations, alongside use of positioning to negotiate roles within the couple dyad, as well as positioning and objectifying of the illness itself. The findings have implications for systemic practice. This requires further exploration with respect to intervention outcomes, national guidelines and providing an evidence base for couples impacted by brain tumour.

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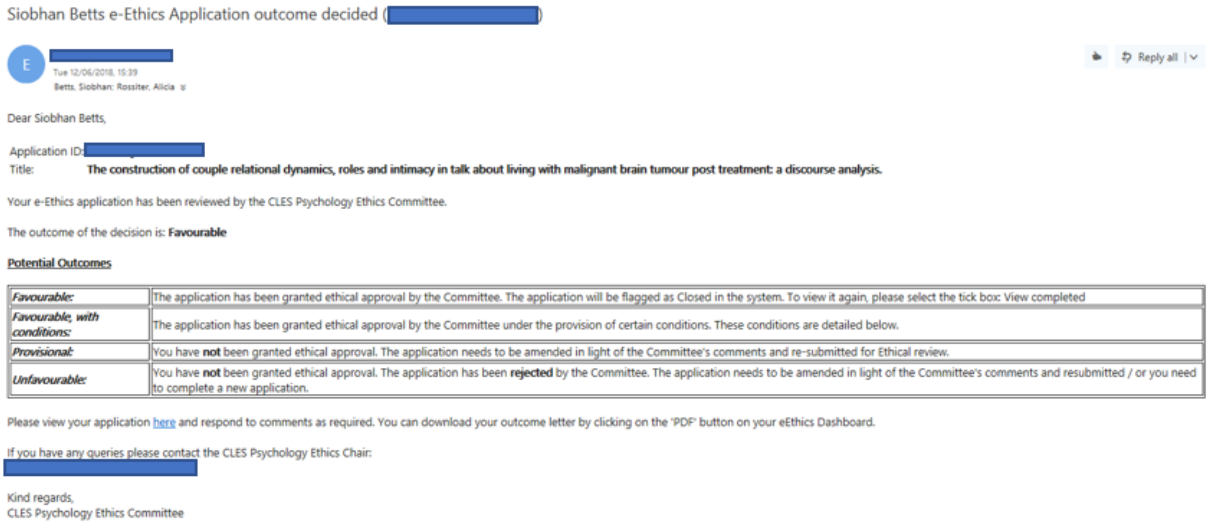
# Appendices

## Appendix A: Ethics application confirmation



Siobhan Betts e-Ethics Application outcome decided ([redacted])

E [redacted]
Tue 12/06/2018, 15:39
Betts, Siobhan; Rossiter, Alicia

Reply all

Dear Siobhan Betts,

Application ID: [redacted]
Title: **The construction of couple relational dynamics, roles and intimacy in talk about living with malignant brain tumour post treatment: a discourse analysis.**

Your e-Ethics application has been reviewed by the CLES Psychology Ethics Committee.

The outcome of the decision is: **Favourable**

**Potential Outcomes**

| | |
|---|---|
| ***Favourable:*** | The application has been granted ethical approval by the Committee. The application will be flagged as Closed in the system. To view it again, please select the tick box: View completed |
| ***Favourable, with conditions:*** | The application has been granted ethical approval by the Committee under the provision of certain conditions. These conditions are detailed below. |
| ***Provisional:*** | You have **not** been granted ethical approval. The application needs to be amended in light of the Committee's comments and re-submitted for Ethical review. |
| ***Unfavourable:*** | You have **not** been granted ethical approval. The application has been **rejected** by the Committee. The application needs to be amended in light of the Committee's comments and resubmitted / or you need to complete a new application. |

Please view your application here and respond to comments as required. You can download your outcome letter by clicking on the 'PDF' button on your eEthics Dashboard.

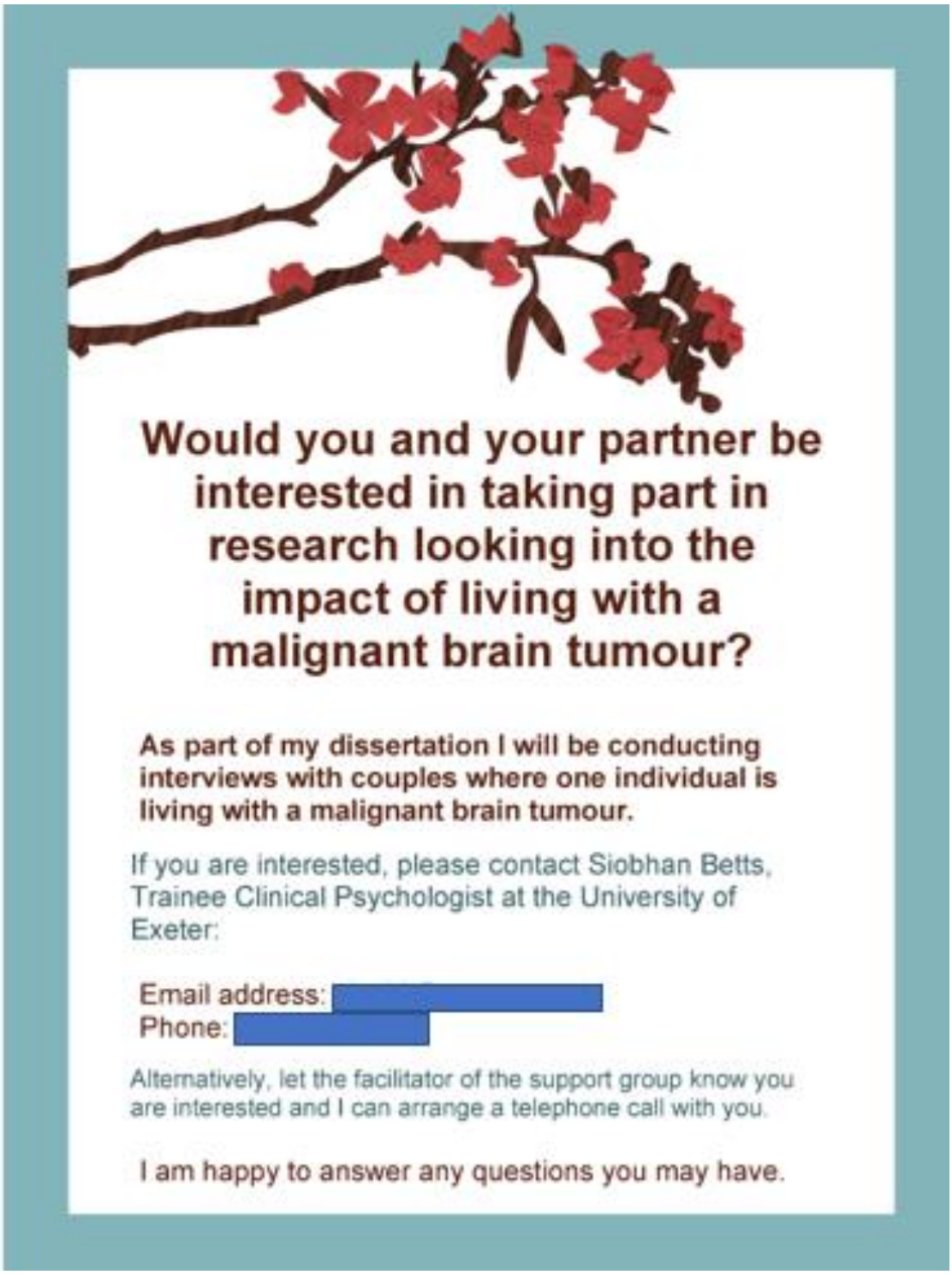
If you have any queries please contact the CLES Psychology Ethics Chair: [redacted]

Kind regards,
CLES Psychology Ethics Committee

### Amendments made and approved:

1) Amendment applied for on the 31st July 2018 to change recruitment so that support workers in the charity could disseminate my research.
2) Amendment applied for on the 21st August 2018 to use an audio-recorder that was not password protected.
3) Amendment applied for on the 24th September 2018 to include patients in the treatment phase of their journey.
4) Amendment applied for on the 13th December 2018 to include Facebook as part of recruitment.
5) Amendment applied for on the 21st January 2019 to include Skype as part of data collection.

## Appendix B: Poster for recruitment



## Appendix C: Reasons for exclusion and drop-outs

- Carer approached researcher; patient deceased: 3
- Carer approached researcher; patient had aphasia or dysphasia: 2
- Mental health difficulties of patient: 1
- Physical health difficulties of patient: 3
- Couple made no further contact after initial contact made: 4
- Brain tumour patient approached researcher; no current intimate partner: 1
- Daughter of father with brain tumour approached researcher: 1

## Appendix D: Information sheet Version 5

### Information Sheet

**Title of Project:** The construction of couple relational dynamics, roles and intimacy in talk about living with malignant brain tumour: a discourse analysis.

**Researcher name:** Siobhan Betts, Trainee Clinical Psychologist, University of Exeter

**Supervisor:** Dr Alicia Rossiter, Clinical Psychologist and Research Supervisor, University of Exeter

**Invitation and brief summary:**

You have been invited to participate in a study exploring couple's experience of living with a brain tumour. Your participation in this study is voluntary. Please do not hesitate to ask questions after you have read the information sheet and take your time to consider whether you would like to participate in the research.

**Purpose of the research:**

As part of my Doctorate in Clinical Psychology at the University of Exeter I am required to complete a major research project. I have chosen to explore the experiences of couples where a member of the couple is living with a brain tumour. I believe it is very important to hear the experiences of the person with the brain tumour and their significant others. There is currently limited research in the area of brain tumour research that looks at the experiences of both the individual living with the brain tumour and their significant other.

**Why have I been approached?**

You and your partner have been approached because you are currently using the services within the [*removed for anonymity*]. The project aims to interview twelve couples about their experiences.

**What will participation involve?**

Participation in the research will involve two meetings, either at your home or at a local venue provided by the [*removed for anonymity*].

The first will be to discuss the research and get your consent for taking part in the research. We will then have a discussion about your experiences of living with a brain tumour. This will last for roughly an hour and a half but this depends on you and your partner and what is discussed. The discussion will be facilitated by myself but will also be led by your discussions.

These discussions will be audio-recorded on a device and the recording will be uploaded on to a secure server as soon as possible after the interview. The device will be transported in a locked box in a locked vehicle.

The second meeting will be a chance to debrief about how you found the discussion and talk about any themes that came up. This is an opportunity for you to learn more about where the research will be disseminated to so it helps to influence professionals and health services.

**What are the possible advantages of taking part?**

We hope that you will find this a good opportunity to reflect as a couple on your experiences and that it will be a generally positive experience. We hope that this research will benefit the wider brain tumour community.

**What are the possible disadvantages and risks of taking part?**

Some of the content that is discussed may bring up difficult emotions for you. If this does happen please let me know and the interview can be paused or terminated. I can provide information about support services available, if necessary. If there is a question that is asked that you feel uncomfortable answering, please let me know and we will be able to move on to another question.

**What happens if I don't want to be part of the research anymore?**

You are allowed to withdraw from the study at any point in the research, without any explanation, and your data will be destroyed.

However, please be aware that once the data is analysed you will be unable to withdraw the data from the study as your data will have been merged with other data to compare and contrast couple's experiences of living with a brain tumour. I will let you know if it is possible for your data to be destroyed or not.

**Will participation in the project remain confidential?**

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection.

Personal information, including names, addresses and hospital information, will not be used in any reports or publications to ensure that confidentiality is upheld.

All data will remain stored on a secure server. The recordings from the interview will be uploaded to the secure server as soon as possible after the interview and the original file will be deleted from the recording device. Data may be transferred to an outside organisation for transcribing, in which case, a highly secure encrypted file transfer system will be used to ensure security and confidentiality.

All the information collected during the course of the research will be kept strictly confidential. However, it is important to know there are limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a healthcare professional about this (this might be your GP or the emergency services). This is part of my duty of care and working within ethical practice for clinical research. I will tell you if I have to do this and we can try to make a plan together.

**Will I receive any payment for taking part?**

Unfortunately, you will not receive payment for taking part in the research.

**What will happen to the results of this project?**

The project will be submitted as part of the portfolio for the Doctorate in Clinical Psychology. The project may be disseminated to academic publishers and the results may be presented at a conference.

**Who has reviewed this project?**

The project has been reviewed by the University of Exeter Research Ethics Committee. The chair of the committee is [*removed for anonymity*], whose email address is [*removed for anonymity*].

Thank you for taking an interest in this research. Please do not hesitate to ask any questions.

## Appendix E: Consent form version 4


### Consent form

I confirm that (please tick each box if you agree with the statement):

| | | |
|---|---|---|
| 1 | I confirm that I have read and understood the information sheet, version 5.0, dated 24th September 2018, and have had the opportunity to ask questions, which were answered to a satisfactory standard. | ☐ |
| 2 | I consent to voluntarily take part in this project. I don't expect to receive any benefit or payment for my participation. | ☐ |
| 3 | I understand that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. | ☐ |
| 4 | I understand that this research is being conducted by Siobhan Betts, a Trainee Clinical Psychologist, as part of the Doctorate in Clinical Psychology. This work is supervised by Dr Alicia Rossiter and Dr Janet Smithson, Research Tutors at the University of Exeter.<br><br>I understand that sections of the data collected may be looked at by members of the research team from University of Exeter and I give permission for members of the research team to look at the data collected. | ☐ |
| 5 | I agree for the interview to be audio-recorded. I understand the device will be stored securely in a locked container until it is saved electronically on to a secure server. I understand that the original recording will be deleted from the device once it has been saved electronically.<br><br>I understand that the audio recording made of this interview will be used only for analysis. I understand that no other use will be made of the recording without my written permission, and that no one outside the research team will be allowed access to the original recording. | ☐ |
| 6 | I understand that my words may be directly quoted and that extracts from the interview may be used in any conference presentation, report or journal article developed as a result of the research. | ☐ |

| | | |
|---|---|---|
| | I understand that any summary of the interview, or direct quotations from the interview will be anonymised so that I cannot be identified, and care will be taken to ensure that other information in the interview that could identify me is not revealed. | |
| 7 | I understand that the audio recording and transcript will be destroyed after a set period of time, as specified by the British Psychological Society's ethical guidance and the University of Exeter policy for postgraduate research. | ☐ |
| 8 | I understand that if the researcher is concerned about risk to myself or others, they may have to break confidentiality and share information with clinical service providers in order to ensure my safety. For example, my GP or mental health care co-ordinator.<br><br>I consent to providing my GP name and contact details. | ☐ |
| 9 | I give permission for my GP to be contacted if the researcher requires information about my brain tumour diagnosis or treatment. | ☐ |
| 10 | I understand that I will receive a debrief following participation in the study and canto request a summary of the research results. | ☐ |
| 11 | I consent to participate in the research. | ☐ |

<u>Please sign below and put the date:</u>

Participant's name:

Participant's signature:

Date:

Researcher's name: Researcher's signature:

## Appendix F: Interview schedule

Interview Schedule

1st meeting

Checklist before the interview starts:

| | |
|---|---|
| | Introduction to the researcher and the purpose of today's meeting. |
| | Discuss that the research includes looking at relational dynamics, for instance intimacy, communication, roles, strengths as a couple. Opportunity to discuss the research project and for participants to ask questions. |
| | Discuss the limits of confidentiality and other ethical issues that might arise. |
| | Check that participants have read and understood the information sheet. |
| | Do participants have capacity to agree to the study.<br>If so, ensure that consent form is signed by all participants. |
| | Ask all participants to complete the PHQ-9. |
| | Ask for details of the GP and gain consent to contact GP if needed. |
| | Check with participants when they would like a break. |
| | Start recording. |

Content of the interview:

- **Please can you briefly tell me your story of being diagnosed, treated for and living with a brain tumour.** [*directed to both patient and carer*].

Researcher's notes about the couple's story for further exploration:

**Initial Question(s)**

- Has your relationship changed in the different stages of living with a brain tumour? if so, in what way?

*Prompts:*

- In what way did your relationship change when you were diagnosed with a brain tumour?
- In what way did your relationship change when you were going through treatment?
- In what way did your relationship change following the treatment of your brain tumour?
- Do you have a specific example of how the relationship has changed?

**Perceived ability to cope**

- Do you think you have supported each other or have been supported by each other? In what ways?

*Prompts:*

- Would you say you have strengths as a couple that have helped you get through this period of managing the brain tumour?

2) Are there any ways you have learnt about supporting each other or yourselves as a couple through the process?

**Communication**

- Would you say the way in which you communicate together changed? If so, in what ways?

*Prompts:*

- (How) did you talk together about the diagnosis and treatment?
- (How) did you share your hopes and fears?
- (How) does that differ to how you communicated before the diagnosis?
- If one, or both of you, have found something difficult, has that been communicated between you, and if so, how has that been communicated? How was that communication received by the other?
- Would you say the way you have communicated about the future has changed?
    - Have you been able to communicate about your anxieties about the future?
    - Have you been able to communicate about your goals for the future or long-term plans that may be less possible due to the illness?

**Roles:**

- Did your roles shift over the course of living with a brain tumour? If so, how?

*Prompts:*

- Can you tell me a bit more about the roles you both have now and if this differs from before the diagnosis and during treatment?
- You say there was a shift in roles over the course of living with a brain tumour. Would you say you negotiated these shifts in roles as a couple? If so, was this negotiation as a couple or alone?
- Was there anything that impacted on making these decisions?
- You spoke about the changes in your roles, were these change in roles communicated?

- Has there been a change in pre-existing parenting roles with the impact of living with a brain tumour?

**Intimacy**

- Did you express intimacy to each other following the diagnosis and during treatment?

*Prompts:*

- Has physical intimacy, such as hugging or holding hands, changed since the diagnosis?
- I notice you haven't talked about sexual intimacy and I wondered whether you have noticed a change in sexual intimacy since the diagnosis, during treatment or following treatment?
- How would you make sense of a change in intimacy related to the brain tumour diagnosis and treatment?

**Support as a couple**

- [If appropriate] as a couple it sounds like you've managed in various ways, what support would you have liked or looking back you think would have been helpful, if at all?

**End of the interview**

- "Is there anything you would like to add?"

2nd meeting

| | |
|---|---|
| | Check in with the couple about how they found the process. |
| | Ask for feedback about how they found the experience and how it could be improved. |
| | Offer the option of having the results disseminated to the couple. Discuss the options available for this. |
| | Offer the couple contact details of support services. |

**Appendix G: Appointment letter**

Doctorate in Clinical Psychology

Washington Singer Building

University of Exeter

Perry Road

Exeter

EX4 4QG

Dear Participants,

Thank you for agreeing to participate in my research looking into the impact that living with a brain tumour has on relational dynamics between couples.

I have sent a hard copy of the information sheet with this letter.

I look forward to seeing you on [date, time] at [venue].

If you are unable to make this appointment, please email me on [*removed for anonymity reasons*].

Yours sincerely,

Siobhan Betts

Trainee Clinical Psychologist under the supervision of Dr Alicia Smith, Clinical Psychologist

University of Exeter

## Appendix H: Transcription Coding

Adapted from Jefferson, 2004

| | |
|---|---|
| (0.5) | Number in brackets indicates a time gap in tenths of a second. |
| (.) | A dot enclosed in brackets indicates a pause in the talk of less than two-tenths of a second. |
| = | 'Equals' sign indicates 'latching' between utterances. |
| [ ] | Square brackets between adjacent lines of concurrent speech indicate the onset and end of a spate of overlapping talk. |
| (( )) | A description enclosed in a double bracket indicates a non-verbal activity. |
| - | A dash indicates the sharp cut-off of the prior sound or word. |
| : | Colons indicate that the speaker has stretched the preceding sound or letter. |
| (inaudible) | Indicates speech that is difficult to make out. Details may also be given with regards to the nature of this speech (e.g. shouting). |
| . | A full stop indicates a stopping fall in tone. It does not necessarily indicate the end of a sentence. |
| ↑↓ | Pointed arrows indicate a marked falling or rising intonational shift. They are placed immediately before the onset of the shift. |
| <u>Under</u> | Underlined fragments indicate speaker emphasis. |
| CAPITALS | Words in capitals mark a section of speech noticeably louder than that surrounding it. |
| ° ° | Degree signs are used to indicate that the talk they encompass is spoken noticeably quieter than the surrounding talk. |

## Appendix I: Dissemination of research

The dissemination of the research will utilise the following avenues: the participants, the brain tumour charity and the wider population.

### Participants

Participants were offered the chance to receive a summary of the results. These will be disseminated to participants in July 2019.

### The brain tumour charity

The results will be disseminated to the CEO of the charity verbally, as well as in written format through the summary of the results. There will be an opportunity for the results to be disseminated to the wider audience within the charity; for example, through my attendance at a meeting or event held by the charity.

### Wider population

The aim is for the research to be disseminated via publication in the journal Neuro-Oncology.

## Appendix J: Instructions for authors submitting an article to Neuro-oncology

Basic and translational investigations and clinical investigations should adhere to the following guidelines:

- 250-word abstract (maximum)
- 150-word (maximum) summary entitled "Importance of the Study"
- 6000-word limit for all words in manuscript file, including abstract, importance, manuscript text, acknowledgements, references, and figure legends
- 6 display items (figures and/or tables)
- 50 references (maximum)

Title page

- Title, not to exceed 160 characters and spaces
- Authors’ full names: given name(s) followed by surname
- Affiliation of each author at the time of the study, including department and institution. If authors are from more than one department or institution, each author’s initials should be placed in parentheses after the applicable address.
- Running title, not to exceed 50 characters and spaces
- Name and complete contact information for the corresponding author, including street address, telephone, fax, and e-mail address
- Footnotes regarding change of address or affiliation, co-first authorship, or new sequence accession numbers

- Statement (titled “Funding”) detailing any funding that supported the research
- Statement (titled “Conflict of Interest”) detailing any conflicts of interest for all authors
- NEW: Statement (titled “Authorship”) detailing the contributions of each author (see Authorship)
- List of any unpublished papers cited (see Unpublished Material under References)
- If applicable, a statement that the paper being submitted is one of a series
- Mention of total manuscript word count, including words in abstract, text, references, and figure legends

Abstract

The abstract should not exceed 250 words. It should be written in full sentences. All abstracts, except those accompanying review articles, should be written in structured format:

• Background : State the clinical (or other) importance of the work. End with a hypothesis or purpose statement (e.g., “The aim of this study was to determine whether…”).
• Methods : Give the materials (or patients) and methods used to answer the research question.
• Results : State the study’s findings. Make sure the results correspond to the methods.

• Conclusions : In a sentence or two, explain how the findings address the purpose of the study. The conclusions should be supported by the results given.

Because abstracts often appear apart from the text of a paper (e.g., in PubMed or Medline), they should not cite references. Keep nonstandard abbreviations and acronyms to a minimum (no more than five in the abstract), defining them in parentheses at first mention. It is essential that the Abstract clearly states the biological importance of the work described in the paper.

Keywords

Below the abstract, list up to five keywords that may be used for indexing.

Key points

*NEW*: Below the key words, list two to three key points that summarize the most important findings of your manuscript. Each of these should be no longer than 85 characters plus spaces. These points may be used to highlight your article on social media.

Importance of the Study

All submissions to *Neuro-Oncology* should include a 150-word (or less) summary entitled "Importance of the Study". This should be placed just after (below) the abstract and keywords and include information regarding the value of the study compared with prior literature as well as future implications. For laboratory studies, a statement addressing the translational significance should be included. There should be no references. The Editors will use this information as part of the evaluation of the paper, and both the editors and peer

reviewers will check the accuracy of the information and may ask for revision. This statement will also be published with the manuscript.

Text

*Introduction* . This section should state the problem or question being addressed and summarize relevant background information to provide context for the research question.

*Materials and Methods*. The explanation of the experimental methods should be brief but adequate for repetition by qualified investigators. Procedures that have been published previously may be described in brief and be cited with appropriate references. Only new and significant modifications of previously published procedures need complete exposition. The sources and manufacturers of special chemicals or preparations used should be named. Some of the methods details (buffer composition, PCR primers, incubation conditions, etc.) may be placed in a Methods supplement but each method must be mentioned in the main manuscript with enough information so that a reader does not have to consult the supplement to understand the procedures. Reference to the supplement should be made in the main manuscript text where appropriate. NOTE: Your ethics statement(s) must remain in the main manuscript.

For experimental investigations of human or animal subjects, state in the Methods section of the manuscript that an appropriate institutional review board approved the project. Investigators who do not have formal ethics review committees should follow the principles outlined in the "World Medical Association Declaration of Helsinki: Research involving human subjects". For investigations of human subjects, state in the Methods section the manner in

which informed consent was obtained from the subjects. Statistical methods should also be clearly and completely described in the Methods section.

*Results*. This section should include a concise summary of the data presented in the tables and illustrations. Excessive elaboration of those data should be avoided. The Results and Discussion sections may be combined if doing so saves space or improves the logical sequence of the material.

*Discussion*. The data should be interpreted concisely, without repeating material already presented in the Results section. Speculation is permissible, but it must be well founded and clearly identified as speculation.

*Funding*. Details of all funding sources for the work in question should be given in a separate section entitled "Funding". This should appear before the "Acknowledgments" section. The following rules should be followed: the full official funding agency name should be given (that is, "National Institutes of Health", not "NIH"); grant numbers should be given in brackets; multiple grant numbers should be separated by a comma; agencies should be separated by a semi-colon; no extra wording such as "Funding for this work was provided by ..." should be used; where individuals need to be specified for certain sources of funding, explanatory text should be added after the relevant agency or grant number "to [author initials]" (e.g., "National Institutes of Health (CB5453961 to C.S., DB645473 to M.H.); Funding Agency (hfygr667789).")

*Acknowledgments (optional)*. An Acknowledgments section (not footnotes) should be included, if appropriate, to recognize the following:

- Special assistance or contributions by non-authors (e.g., supply of materials or editorial support)

- Previous presentation of the material at a meeting, workshop, or other event

Personal acknowledgments should precede those of institutions or agencies. Please note that acknowledgment of funding bodies and declarations regarding conflict of interest should be given in separate Funding and Conflict of Interest sections on the title page (see above).

*References* . See "References" for specific instructions.

*Figure Captions* . Figures should be numbered sequentially with Arabic numerals. Figures may have subparts (A, B, C, etc.); each subpart should be described in the caption. See recent issues of the journal for examples of acceptable styles.

Captions are required for all figures and should be typed, double-spaced, after the list of references. Captions should briefly describe the data shown and should not repeat details given in the text. Include the type of staining, magnification, and similar information required for accurate interpretation where applicable. Each caption should adequately identify all symbols (where not defined on the figure itself) and abbreviations used in the figure. Captions and symbols should make the figure interpretable without reference to the text. Figure numbers or captions should not be included on the face of an illustration.